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Conflicted Cure: Exploring Concepts of Default & Adherence in Drug Resistant Tuberculosis Patients in Khayelitsha

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ABSTRACT

This dissertation examines default and adherence in drug-resistant tuberculosis (DR-TB) patients in Khayelitsha, Cape Town, South Africa. The ethnographic data is drawn from three and a half months of participant-observation, illness-narrative interviews, in-depth interviews, focus groups, support-group sessions and creative methodologies such as collage and emotional mapping. The various methods revealed some contradictory experiences with treatment and cure that some patients faced when undergoing treatment for DR-TB. Through an analytical framework of affect and emotions, this paper traces the complexities and disparate conceptions of default and adherence that circulate amongst patients. This paper argues that default and adherence do not operate in isolation but are part of dynamic entanglements of relationships and self-introspection that surface throughout the course of treatment for DR-TB.

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INTRODUCTION



Figure 1 Khayelitsha

An informal conversation with a Cape Town public-health official made a considerable impact on the way I frame this research. With some frustration she described an incident with a young woman who had DR-TB and used her disability grant¹ to buy a graduation dress for her daughter living in the Eastern Cape. Subsequently she interrupted her treatment to deliver the gift. Upon her return to Cape Town she was told that she had ‘defaulted’ on her DR-TB treatment and, according to the public-health official, she could not comprehend how this was possible. She believed that she was consistent with her medication and merely took a break from her medication to visit her daughter. The patient’s pause in her treatment was incomprehensible to the public-health official. This example demonstrates the disparate perceptions of default and adherence in DR-TB treatment among patients and public-health officials. My dissertation aims to address the various understandings and perceptions of

¹ DR-TB patients receive a temporary disability grant for six month to one year while they are on treatment (TAC 2009).

² The Population Registration Act (Act No. 30) in 1950 categorised the entire South African population into three racial categories, ‘White’, ‘Black (African)’ and ‘Coloured.’ Subsequently, the Group Areas Act

treatment adherence. It is my view that a simple question such as “Why do some individuals adhere to treatment while others do not?” oversimplifies a complex discussion about how default and adherence are understood by individual patients through personal experiences, emotions, relationships and capabilities. By analyzing affect and emotions, this dissertation will explore the relationships that evolve throughout a patient’s DR-TB treatment regimen. I will explore patients’ relations to other patients, their kin and medical personnel, the relationships that patients have with their medication and their relationship with themselves (identity formation).

I titled this dissertation “Conflicted Cure” as a way to address the suffering that some patients undergo throughout their treatment, as well as the hardships that medical practitioners encounter in delivering care. The cure for DR-TB includes a series of contradictory experiences, for example many patients described that the medication made them feel worse than the infection itself. Exploring matters of adherence requires a contemplation of temporality as the time spent in treatment was sometimes described as a place of in-between sickness and health. One interlocutor said, “Life goes on, but TB doesn’t let people start their life.” I believe this was an astute assertion that describes the polymorphic nature of adherence and default. During a period of “waiting” for one’s life to begin the demands of everyday living persist. In order to continue “living,” pausing one’s treatment might be the only coherent option for some patients. This dissertation is therefore situated in the “in-between” of infection and cure or, in Victor Turner’s terms, in a state of “betwixt-and-between” (Turner 1979: 465). It is organised into several vignettes that describe the conversations and encounters of patients and nurses with default and adherence. It will demonstrate that following the prescriptions for DR-TB treatment can radically disrupts a patient’s social order.

From March to June 2012 I drove thirty kilometers daily east on the N2 highway from Cape Town to Khayelitsha, a peri-urban township in the Western Cape. The N2 is densely lined with formal and informal housing demarcating the expansive Cape Flats region. This acts as a visual reminder of the extreme polarisation of wealth and poverty throughout the city. Eighteen years post-apartheid South African cities remain socially and spatially divided. Racial segregation was exercised during the apartheid regime and in 1950 the government passed the

Group Areas Act (Act No. 41), which deployed rigid strategies to divide the population based on racial lines. The division forced “African” and “Coloured”² residents in previously well-established communities to relocate to townships in the Cape Flats (Wilkinson 2000: 197). Khayelitsha, which means “New Home” in isiXhosa, is one of the fastest growing townships in South Africa with an estimated 800,000 residents (Lemanski 2007, Govender, Barnes, Pieper 2011, Wilkinson 2000). It is one of the more recently developed townships, initiated in 1983 as a way to consolidate the “legal” Africans residing in the existing settlements in order to establish a Black residential area (Spiegel & Mehlwana 1997: 4).

Currently Khayelitsha’s spatial geography reads as a mixture of formal and informal housing (shacks). It has some of the highest rates of DR-TB and HIV in the country and around the world (MSF 2011: 7). A pilot project run by Medicines Sans Frontières (MSF)³ in collaboration with The City of Cape Town, and the Provincial Government of the Western Cape began in 2007 (South African Department of Health (SADoH) 2011: 7, MSF 2011). Statistics demonstrate that the pilot project has been successful in increasing case detection, initiating patients on proper drug therapy and decreasing mortality in infected patients (MSF 2011). However, in 2008 there were 6,000 cases of TB notified in Khayelitsha and an increased detection of DR-TB (Cox et al. 2010: 13901). Prior to the pilot project, patients were only screened for DR-TB if they had been previously diagnosed with TB, but a survey conducted by MSF and the City of Cape Town DoH reveal that half of the new cases of DR-TB in Khayelitsha had never previously had the infection (MSF 2011: 4). The distinction between drug-susceptible TB and DR-TB is that TB treatment takes approximately six months to cure while DR-TB takes an average of eighteen to twenty-four months. It was believed that DR-TB was caused by non-adherence to treatment or treatment interruption, but research demonstrates that DR-TB is transmitted the same way as TB. This reality escalates the pressure for rapid diagnostics and shortening the delays to admitting patients to treatment. Despite the advancements in DR-TB treatment in Khayelitsha there remains a multitude of complications. One of the most notable challenges is patient adherence.

² The Population Registration Act (Act No. 30) in 1950 categorised the entire South African population into three racial categories, ‘White’, ‘Black (African)’ and ‘Coloured.’ Subsequently, the Group Areas Act established zones whereby one racial group would reside (O’Malley).

³ MSF is a medical humanitarian organisation that delivers emergency medical care to people in conflicts, natural and man-made disasters and epidemics.

This dissertation is located in Khayelitsha and positioned in the nexus of South Africa's DR-TB public health crisis alongside individual patients' ideas on adherence and default in relation to their DR-TB drug regimen. Cape Town is an unequal setting where disease incidence is most significant in townships such as Khayelitsha. The bureaucratic dilemmas are sustained by mismanaged TB interventions, lack of resources and political will, and individual patients' treatment-seeking behaviour. Currently, one of the most pronounced challenges affecting public health's TB interventions is patient treatment adherence. Non-adherence to drug regimens is not a unique phenomenon to DR-TB therapy – it is well documented in literature on the birth-control pill, hypertension medication and antiretroviral drugs (Hall et al. 2010, Sellier et al. 2006, Tollman et al. 2008). However, given the mode of transmission and contagiousness of TB, adherence to TB-drug regimens presents distinct challenges to public health interventions. DR-TB is curable, but those delivering treatment observe that some patients do not comply with the biomedical prescriptions and routines that would cure them. This carries profound consequences as it jeopardises the health of the individual patient and constitutes a threat to the wellbeing of others. A process of weighing individual human rights alongside responsibilities toward the collective wellbeing is at the forefront of the contentious debates on TB-infection control and treatment delivery.

WHEN OUR BODIES BETRAY US

Medical interventions for DR-TB most often provide a cure for those who are infected, in the event that the patient takes his or her medication in the prescribed fashion. However, it was evident throughout this research that a patient's personal approach to infection control may differ from the professional (nurse, public health, physician) strategies in everyday practice. Through public health strategies DR-TB cure is often presented as a moral choice, indicating that there is a clear distinction between good and bad patient behaviour. The terms 'default' and 'adherence' suggest that there are fixed classifications for patient treatment-seeking behaviour. The restrictive quality of such terminology allows for a single reading of default and adherence through its biomedical connotations rather than demonstrating that they exist on a continuum where patients move in-between the categories to encompass strategies

and practices that reflect their immediate needs. The example of the patient who “paused” her treatment to visit her daughter in the Eastern Cape reveals how patients’ understandings of default and adherence are often incongruous with public health and biomedical definitions.

Recognising this discord and disparity in patients and health-care providers propelled me to explore theories of emotions and affect as a way to grapple with these complexities. My theoretical foundation for this dissertation is predominantly inspired by the concept of “radical empiricism” which was developed by the nineteenth century pragmatist philosopher and psychologist William James. Radical empiricism is a response to rationalism which, according to James, is concerned with universals, whereas empiricism is influenced by the relational elements that create the whole, in other words, the particularities. What makes empiricism radical is its emphasis on experiential encounters. James considers this as “mosaic philosophy” dedicated to the pluralities in everyday relations and experiences (Jackson 2007: xvii, James 1968: 21). Radical empiricism is about the relations between people and about the relations between people and materiality or the environment, and each relation carries equal value to an individual’s experience (Davies 2010: 23). I attempt to describe and engage with what happens “in-between” infection and cure, or what emotional processes and affective states occur in the “waiting for one’s life to start” while on DR-TB treatment. This relational aspect of radical empiricism allows me to consider the multiple dimensions that make up the vast experiences that patients and health care providers have with DR-TB treatment.

Applying this as the foundation to my dissertation lets me approach patients’ emotions and physical side-effects as forms of knowledge and consider how affect manages or influences certain patient reactions. In its most fundamental sense, affect is about connecting and reacting to the outside world in particular ways (James 1968: 74). In order to elaborate on affect one must look at its basic philosophical definition: “the inner motive as distinguished from the intention or end of action” (Runes 1962: 6). This definition is derived from the Spinozian explanation of *affectus*, which denotes sentiment or feeling, referring to a kind of thought that is not necessarily represented through an objective reality (Deleuze 1978: 1-4). From this assessment, affect precedes our ideas or understandings of certain realities or encounters and mediates a body’s actions. This is drawn from Spinoza’s illustration: “by affect

I understand the affections of the body, by which the power of acting of the body itself is increased, diminished, helped, or hindered, together with the ideas of these affections” (Spinoza 1958: 207). In examining default and adherence various elements such as drug side-effects, living conditions, nurse-patient relationships and family relationships all influence a patient’s approach to his or her treatment. Affect is coextensive with the body and Bruno Latour’s reading of William James offers an insightful interpretation of how the body “learns to be affected.” The significance of James’ perception of the body is the acknowledgement that “to have a body is to learn to be affected, meaning ‘effectuated,’ moved, put into motion by other entities, humans or non-humans” (Latour 2004: 205). There is a conviction that affect is exhibited through a state of “in-between-ness” where the body’s potential is marked through its capacities to be affected and to affect (Seigworth & Gregg 2010: 2). It is in this uncertain line of “in-between-ness” where the body learns how to be affected and directs itself either consciously or unconsciously to develop certain “techniques of the body” (Latour 2004: 205, Mauss 2007: 50). Individual patients are affected by varying forces and affect is entwined with emotion through our senses. Ben Highmore explains that affective forces encounter a sensate body that is moved or motivated by sentiment (2010: 120-121). Lawrence Grossberg explains, “It is about how you can move across relationships, where you can and cannot invest, where you can stop/rest and where you can move and make new connections, what matters in what ways” (2010: 313). Emotions in this sense are not merely a design of affect, but rather a way of comprehending affective forces (Grossberg 2010: 316). This dissertation will investigate three main aspects of emotions and affect – patients’ relations to others (other patients, kin and medical personnel), the material relations between patients and their medication, and patients’ relations to themselves (identity formation) – by analysing how these encounters affect patient adherence and what emotional utterances were used to describe those experiences.

CHAPTER OUTLINE

In the following chapters I explore various aspects of default and adherence to DR-TB treatment. The first chapter offers a contextual foundation for the remainder of the dissertation. It outlines the global and national TB and DR-TB situation and offers an explanation of the differences between the various strands of TB and their treatment strategies. I will problematise default and adherence to show that they are part of a continuum of personal introspective reflections, rather than a dichotomous choice. The historical and contemporary realities of TB and DR-TB are directly linked to issues of poverty. The intricate patterns of default and adherence can be read through some patient's descriptions of increased responsibility to treatment protocols alongside the reduction in bureaucratic responsibilities.

Chapter Two details my ethical position and the methodological strategies that were developed with participants in the field as well as some creative strategies to address theories of affect and emotion. It also explains the ethics of my decision to bear witness to DR-TB in Khayelitsha.

Chapter Three traces a series of relationships between nurses and patients and between patients and their kin to reveal the moral economy of expected behaviour for DR-TB patients. A rhetoric of blame circulated amongst patients and health-care workers when patients deviated from their prescription. However, private conversation revealed that there are various understandings of cure, which may include suicide as one aspect of healing or escape.

Chapter Four examines the material act of swallowing pills and the 'tailored' practices that patients develop in order to regain a sense of control over their bodies. By tracing the illness narrative of one female patient I was able to explore how DR-TB treatment embodies contradictory outcomes in some patients, whereby a dual process of cure and 'toxification' competes within one body.

CHAPTER I

CONTEXTUALISING TUBERCULOSIS: GLOBAL & LOCAL REALITIES

THE GLOBAL RESURGENCE OF TB & EMERGENCE OF DR-TB

Tuberculosis can infect anyone, but for centuries it has been linked to poverty. The world's most vulnerable populations are at the greatest risk of contracting the infection. Ninety-five percent of the global TB cases are found in low- and middle-income countries and these cases contribute to ninety-eight percent of all TB deaths (Benatar & Upshur 2010: 1217). Living conditions for those most susceptible to TB are comparable to the housing conditions in the pre-industrial revolution throughout England and Europe, a period when those populations were scourged by TB (ibid: 1218). Overcrowding, unemployment, poor nutrition, inadequate health-care services and under-resourced hospitals and clinics remain a distinguishing feature of the high prevalence of TB in low- and middle-income countries (Farmer 2010). The socio-economic impact of TB in poor and vulnerable households amplifies inequalities, as patients are required to suspend employment whilst on treatment (Kamineni et al. 2012: 2). The complexity of TB and DR-TB treatment initiatives is directly related to the fact that many TB policy initiatives fail to integrate poverty alleviation. In order to move beyond conversations about pro-poor strategies for infection control, governments and local and international NGOs must use an integrated approach to treatment that considers poverty alleviation as equally significant to infection control and biomedical diagnostics (Benatar & Upshur 2010: 1218). This chapter will offer a contextual backdrop to the global and national TB and DR-TB realities and highlight the biomedical language that is employed to classify patients' treatment-seeking behaviour. In the post-antibiotic era, policies and political biomedical language encourage a rhetoric that places increased responsibility on individual patients and households while ignoring the role that governments, pharmaceutical companies and national and international organisations have had, both historically and contemporarily, on the high prevalence of TB and DR-TB. Language such as 'default' and 'adherence' is used in a way that that generates public perceptions of personal accountability for one's treatment and fails to

hold bureaucratic bodies to same level of accountability as individual patients, households and communities.

In 1993 the World Health Organization (WHO) declared TB a global emergency. The current re-emergence of drug-susceptible tuberculosis (TB) and the spread of drug-resistant TB (DR-TB) can be regarded as one of the greatest failures of social and medical interventions worldwide (Benatar & Upshur 2010: 1218, Cummings 2007, Singh et al. 2007). Treatments for the infection have progressed through a range of strategies that have been notable medical triumphs around the world (Cummings 2007: 683). There was a significant decrease in TB cases throughout Europe during the 1950s which was largely due to the heralded successes of combined chemotherapy⁴ and better nutrition and housing conditions (Bryder, Condrau & Worboys 2010: 6). Regrettably, the resurgence of TB and escalating cases of DR-TB around the world have been caused by poor management of the infection, inadequate access to effective and quality treatment, interruption in drug supplies and the prevalence of HIV/AIDS (Aziz & Wright 2005: 259, Farmer 2010: 1222). In 2009, the WHO reported 9.4 million cases of TB around the world, with the highest incidence in India, China, South Africa, Nigeria and Indonesia (2010: 7). Of the 9.4 million cases, 1.1 million were reported to be HIV-positive, of which 80 percent were from African countries. Approximately 500 000 cases of DR-TB were reported in 2008 with the highest prevalence found in China, India, Russia and South Africa (Lawn & Zumla 2011: 57, WHO 2012: 7). The co-infection rate of TB and HIV is extremely high; immunocompromised individuals are more likely to develop an active form of the bacillus. Both drug-susceptible and -resistant strains of TB are cause for alarm; TB is an airborne disease spread by someone with an active form of the infection through coughing, sneezing, talking, singing or exhaling. Approximately 2 billion people are infected with a latent strain of TB, but only ten percent of those individuals will develop an active form of the infection (DoH 2004: 12). The development of infectious TB is most likely to occur in the first few years after exposure, making it difficult to track not only the source of infection, but also the time (Lawn & Zumla 2011: 61).

⁴ S.A. Waksman discovered the first anti-TB drug in 1943. Clinical trials revealed some resistance to the medication and in 1946 a Swedish scientist, Jürgen Lehmann, created Para-amino-salicylic (PAS) another anti-TB drug, proven to be effective when combined with streptomycin. In the early 1960s it was believed that the implementation of chemotherapy drug regimens for TB would eradicate the illness altogether (BMJ 1966, 691; Bryder 1988, 253-265).

Treating drug-resistant TB requires different approaches and considerably more resources. In 2010-11, the cost of treating TB averaged US\$19 per treatment, compared to an average of \$9,000 for DR-TB (MSF 2011: 4). TB takes an average of six months to treat, whereas DR-TB takes eighteen to twenty-four months. Throughout this dissertation, for the sake of clarity I do not distinguish between MDR-TB (multidrug-resistant) and XDR-TB (extensively drug-resistant) as both strains are curable and require two years for complete treatment. It has also been identified that the label XDR still signifies an incurable strain of TB and therefore can promote stigma from healthcare providers and communities. Although both MDR and XDR can be cured, they require different drugs for their treatment. In some cases XDR can progress to “treatment failure”, indicating that there are no treatment options available to the patient. Most commonly, DR-TB cases have been known to emerge through acquired resistance in previously treated TB patients, the drug resistance arising due to an interruption in the drug supply, poor case management or non-compliance from the patient. Primary resistance occurs in patients who have not been diagnosed or treated for TB, which suggests that DR-TB can be transmitted, not just acquired (Aziz & Wright 2005: 258, Cox et al. 2010: 7, Lawn & Zumla 2011: 59, Pepper et al. 2007: 984). In cases of MDR-TB, the patient is resistant to two of the first-line anti-TB drugs (Isoniazid and Rifampicin), while with XDR-TB patients are resistant to the two first-line drugs, one from the Fluoroquinolones line, and also to at least one of the three injectable second-line drugs (Capreomycin, Kanamycin, Amikacin) (CDC 2010: 1, MSF 2011: 4). The second-line drugs are less effective and less tolerated than the first-line anti-TB drugs, therefore making it more difficult to keep patients on the prolonged treatment regimen (Pepper et al. 2007: 984). There are only two lines of drugs to offer TB patients, which limits the options and resources available.

TREATMENT STRATEGIES

Treatment strategies for DR-TB carry complex ethical and human-rights issues. Public health measures around the world have favored quarantine for infectious individuals to prevent transmission and monitor patient compliance (Barnes 2010: 54, London 2009: 1201). Public health strategies weigh individual human rights against the public interest and safety. Examining risk from a population perspective leans toward policies of involuntary detention of infected individuals to protect the broader population (Singh et al. 2007: 0023). The restriction of patient mobility has a profound impact on healthcare services, healthcare providers and patients themselves. Beyond negotiating human-rights discourse, it is also a question of economic and human resources. In resource-poor countries a shortage of hospital space limits infected patients' access. Additionally, nosocomial⁵ transmission has considerable effects on patients and healthcare providers (London 2009: 1203). The WHO launched DOTS (directly observed treatment, short course) in 1996 as way to offer ambulatory care for TB and DR-TB patients, while maintaining a degree of surveillance of infected individuals. Patients are required to travel to their local clinics daily to be given their medication and are observed taking their pills by a registered nurse (DoH 2011, Harper 2005, MSF 2011).⁶ Challenges to patient compliance remain a paramount issue in the application of DOTS, as it demands considerable time, energy and finances from patients to present themselves at a clinic over an extended period of time (Cox et al. 2008: 486).

DR-TB IN SOUTH AFRICA

The current state of TB in South Africa can be read as a product of the colonial incursion and South Africa's apartheid regime. European colonists brought TB to South Africa in the seventeenth century, leading to high rates of infection in unexposed black populations (Malowany 2000). The development of the mining industry in the nineteenth century resulted in an increased prevalence of TB due to overcrowded hostels and poor nutrition and working conditions. Mine workers' migration patterns facilitated the spread of TB from urban to rural

⁵ Infections that occur in hospitals.

⁶ The initial phase of DR-TB treatment requires at least six months of DR-TB injections combined with second line anti-TB drugs. This phase is the most critical and where patients experience the most adverse side-effects (MSF 2011: 17).

areas across the country (Karim et al. 2009: 3-4). The notification of TB was at its highest in the 1960s and saw a rapid decline in the 1970s when certain regions of the country were proclaimed “independent states” and were omitted from South Africa’s statistical data (Edginton 2003). The emergence of HIV/AIDS in the 1980s and 1990s further exacerbated the prevalence of TB in South Africa. The presence of TB, DR-TB and HIV are embedded in the historical legacy of apartheid, as the state segregated populations based on racial lines and limited access to resources, entrenching social and economic inequality throughout the country.

Approximately 13 000 new cases of DR-TB are reported in South Africa every year, creating a threat to the progress made in managing HIV/AIDS throughout the country (Cox et al. 2010: 1). The presence of TB and DR-TB correlates with the socioeconomic conditions of the population, as well as with high rates of HIV/AIDS. Cities in post-apartheid South Africa remain deeply divided despite many efforts to extend economic development opportunities to the poor. The health of the South African population is still embedded in the political economy of disparate healthcare services (Gibson 2001). Consequently, TB, DR-TB and HIV are most pronounced amongst the urban and rural socioeconomically disadvantaged (Marks 2002: 15, Wilkinson 2000: 200).

In the past the South African government was criticised for its draconian strategy to DR-TB, whereby patients were involuntarily hospitalized for the course of their treatment regimen. Patients frequently escaped to return to their families or to work. This resulted in the South African government expending more resources in keeping patients detained than in developing quality TB-treatment strategies (London 2009: 1204). Following an international trend to scale-up DR-TB diagnosis and treatment initiation, the South African National Department of Health is de-centralising TB care. This shift in TB policy is a response to long waiting times for hospital admission and initiation onto treatment, nosocomial transmission, and high default rates of those who commence treatment. For example, in 2010 around 10,000 MDR-TB cases were diagnosed in South Africa, but only half were put onto treatment (SADoH 2011: 5). Patients are most infectious if they do not receive a drug regimen, hence the importance of delivering proper treatment to the greatest number of people (ibid: 14).

DEFINING DEFAULT AND ADHERENCE

Even with the implementation of de-centralised models of TB care and DOTS, patient compliance to treatment regimens alongside efficient and sensitive healthcare systems remains a challenge to the efficacy of such programmes. De-centralised TB care requires a commitment from both the patients and healthcare providers in order for the programme to be successful. Poor adherence is multifaceted and its causes are diverse, including side-effects, social stigma, and patient relationships with healthcare providers, employment and socioeconomic conditions (Queiroz et al 2012: 373, Thiam et al. 2007: 380). The language of TB treatment is saturated with blame of individual patients, placing full responsibility on the patient rather than the quality and efficacy of the healthcare services (Queiroz et al 2012: 375). The most common language used to describe patient behaviour expresses the categories of “default” and “adherence.” Compliance or adherence to a prescribed drug regimen is critical not only for an individual to be cured of their infection but also to minimise the risk of the development of drug resistance.

Polarising patients as either ‘adherent’ or ‘defaulting’ has specific linguistic strength in its functional properties. These categories aim to prescribe “good-patient” behaviour and promote a lifestyle that will assist patients in being cured (DiGiacomo 1992: 122-123, Resnik 1995: 125). Phil Brown wrote a paper on the relationship that medical diagnoses have with the development of such social and political labels. Brown recognises the symbiotic connection between the *social construction of medical knowledge* and the *social construction of illness*: the way patients experience and cope with their disease is often shaped by the medical knowledge attributed to the initial diagnosis (Brown 1995: 37-39). In cases of DR-TB, treatment adherence is critical to curb the spread of infection and to minimise the risk of becoming a ‘treatment failure.’ An adherent patient is someone who takes his or her treatment at the ‘right’ time, with the ‘proper’ dosage and for the ‘entire’ duration of his or her drug therapy. A standard inference of nonadherence is known as interruption or the abandonment of the curative drug regimen for TB for the period of two months (Greene 2004: 402, MSF 2009: 14-15). The example of the woman who went to visit her daughter in the Eastern Cape

illustrates a biomedical ‘defaulting’ patient given the period of time she ‘paused’ her drug therapy. A ‘treatment failure’ is constituted when someone presents a culture-positive sputum in the last three months of drug therapy or throughout the entire course of treatment, indicating that both first- and second-line anti-TB drugs are not sufficient to provide a cure (Brust et al. 2010: 414).

Adherence and default do not operate in isolation. They include a variety of elements from personal behavioural characteristics to socioeconomic conditions (Sumartolo 1993: 1311). An understanding of patient adherence has to include a multidimensional perspective on the patient’s knowledge of the infection, his or her socioeconomic conditions, familial and community relationships, social setting and emotional and psychological wellbeing. Individuals may have varying points of view as to what it means to be adherent or defaulting relative to their current situation or personal priorities. A study on DR-TB treatment adherence in Morocco revealed that lack of knowledge about the infection significantly shaped a patient’s treatment-seeking behaviour (Dooley et al. 2011: 4). A lack of knowledge or understanding about the infection increased a patient’s likelihood to ‘default’ on his or her treatment (ibid: 4). Many of my illness-narrative interviews revealed that some patients with DR-TB had never heard of the DR-TB prior to diagnosis. An interview with a nurse revealed that education and knowledge about the infection are essential to influence treatment-seeking behaviour. The nurse said,

Defaulting is very high. It’s an illness that needs to be cured and it will only come with an understanding of the condition or infection. Once it is made known to the public then they will get to know it more. We can sing about HIV, there is a lot of awareness but not for MDR and XDR. They know about TB but they still don’t know about MDR. They only grasp the TB part. It’s not made very public. So when a person has it it’s overwhelming when it is explained. [...] The language is limited and when you try to explain it you often end up confusing them more... Confusion... Confusion... Confusion.

Lack of information about DR-TB can contribute significantly to nonadherence. It is known that high rates of default often occur in the first few months of treatment, either as a result of profound side-effects or because a patient begins to feel better (Dooley et al. 2011: 414). A

DR-TB patient who was cured from infection in 2011 spoke to me about his reaction to the biomedical terms associated with patient treatment-seeking behaviour.

If you look at the health terminology in Xhosa you will see that it's totally different. You find that perhaps Xhosa might have better words that brings us to understanding or sensitivity about an illness or behaviour rather than the English medical words. There is no such thing in Xhosa as a treatment failure. If there is someone who can't be cured, you look somewhere else. There is no such word or case where people are incurable in Xhosa. Even if it's resorting to faith, but it's not the declaration of death. NEVER. It's never the end of the line.

The examples offered by the nurse and the cured patient demonstrate the paradoxical usage of biomedical classifications within the medical community and those who receive care. The functional aspect of biomedical language cannot be dismissed, as it seeks to prescribe behaviour that promotes treatment-adherence (Resnik 1995: 120). It is critical that patients follow the prescriptions from their healthcare providers to limit the possibility of developing further drug resistance. However, what the language fails to accommodate is the complexity of people's daily lives, which become increasingly problematic when patients begin a DR-TB drug regimen. The tone of the language can encourage blaming a patient for not following the treatment protocol, yet it fails to address the structural barriers to treatment (Stephens 2003: 76). Many patients adhere only after experimenting and trying out different dosages with their DR-TB prescriptions.

This chapter provided a historical and contemporary review of TB and DR-TB on a global and national scale. What is evident in past and present readings of TB policies and infection control is that poverty cannot be excluded from infection-control initiatives. Public-health language such as default and adherence encourage blaming individual patients for treatment compliance without holding bureaucratic institutions to the same measure of accountability. Default and adherence come to mean different things to those seeking treatment. The meanings of default and adherence are shaped and reshaped based on socioeconomic status, family responsibilities and employment opportunities (Winterton 2010).

CHAPTER II

SITUATING WITNESS: ETHICS & METHODOLOGY

ETHICAL POSITIONS

I would wake gasping for breath after imagining my lungs slowly filling with water. A recurring dream about drowning surfaced in my sleep every few nights throughout the course of my fieldwork. I would dream that I was standing in a small room devoid of any windows or doors, while my closest family and friends surrounded me. Gradually my lungs would fill with water and the liquid would begin to drip from every orifice in my body, streaming from my eyes, ears and mouth, we watched the water pool at my feet. The room would begin to fill and there was nowhere to escape. At the end of each dream I would drown everyone I love.

[Field Notes]

I became increasingly mindful of my personal recurring dreams that were obviously connected to my work on TB. These dreams alerted me to my repressed anxieties about infection, mortality and loss during my research. Confronting my dreams about contracting TB and being responsible for the death of my family and friends has influenced the ways I write and engage with the conversations I had during fieldwork. Other anthropologists have used “extraordinary” experiences of fieldwork such as dreams and visions as part of the empirical data gathered throughout their research (Davies 2010: 13, Jackson 2007, Taussig 1992). James Davies proposes that dreams and visions create a “perceptual shift” in the fieldworker which can generate a deeper understanding for the interlocutor’s perspective (2010: 92). For me, the dream did two things. Firstly, it encouraged me to consider what it means to engage with people through their vulnerabilities, people with whom I have very little in common. Secondly, the dream reminded me that in sickness or if threatened, regardless of culture or socioeconomic status, our fears and anxieties are alike. In this spirit I tried to emulate the sensitive and eloquent modes of engagement that Patricia Henderson performed throughout her fieldwork with those living with HIV/AIDS in South Africa. Through an ethics of care, Henderson allows her interlocutors to set the pace of the research and she embraces and

respects the silences they need (Henderson 2012, Winterton 2010). The conversations I had with my research participants were disquieting as they often encompassed complex ideas about suffering, to which all I could do was listen. These conversations spanned several days or weeks to allow for the rhythms and interruptions of everyday life. The silences said more than speech, for it was in these moments where a mutual understanding emerged in which nothing could or needed to be said (Winterton 2010: 10).

Over several weeks of accompanying those who invited me into their homes and lives we developed relationships of respect. One encounter during my fieldwork was particularly significant in the evolution of these relationships, and it occurred in my absence. I became sick with a seasonal flu that kept me away from Khayelitsha for two weeks. I informed everyone that I would return when I got better. In that time I received a flurry of text messages from people I had been working with, as they were concerned that I had actually contracted TB. This worry also occupied my own thoughts, although I had taken all the necessary precautions, such as wearing a mask and conducting interviews and conversations in well ventilated areas. What was interesting was that once I recommenced my fieldwork there was an ease with which participants approached our conversations. It was the recognition of our mutual vulnerabilities to sickness and shared risk that reshaped the level of engagement. It was an equalising moment for some. One text message from a research participant read, “I can see you r just like us.” I am not suggesting that our equality extends beyond our mutual susceptibility to DR-TB, as my social and economic circumstances differ drastically from those I met in Khayelitsha. However, by focusing on the particular distress about DR-TB infection, I was asked to imagine how I would cope, how I would adhere, to whom I would disclose and who would support me. Through convivial discussions with research participants I realised that if I were to contract DR-TB I would confront events and circumstances that would force me to grapple with similar questions. Lila Abu-Lughod insists that in paying attention to the particularities of people’s everyday experiences there will be moments of extreme difference, but on a daily basis people’s encounters are similar: experiences of loss, laughter, frustration and joy suggest that “others live as we perceive ourselves to be living” (1993: 27). Lwazi, an interlocutor, and I shared many conversations about poetry and music. He once said to me, “I know you love music. If you knew that you may become deaf because of a treatment, would

you be willing to give up sound?”⁷ Surprisingly, I replied, “I don’t know. I can’t imagine my life without it.” Months passed and this question still weighs on my consciousness, and when I have asked similar questions of others not infected with TB they are usually quick to answer that they would be happy to give up sound to save or extend their life. However, in my research and upon reflecting on my personal experiences I have come to know that these questions never carry a simple response.

In sickness and in healing, life takes new forms. My aunt died of cancer despite undergoing years of agonising chemotherapy and radiation, not necessarily to save her own life but to prolong it for the sake of her children. A friend discontinued chemotherapy at the age of thirty-two, against the wishes of her doctor, family and friends, so she could find some strength to travel before she died. Decisions about treatment and extending one’s life are convoluted deliberations on one’s feelings about one’s own life. I had conversations with patients undergoing treatment for DR-TB that revealed feelings about their past, present and future, and all of these moments in a patient’s life appeared integral to developing an understanding of their changing patterns in their treatment-seeking behaviour. For this reason I cannot include the narratives of all of my interlocutors, as I believe that in order to have a holistic account of people’s experiences with TB, their narratives cannot be restricted to the current diagnosis. Ethical research is about more than signed and written consent, it is also about patience, interpreting silence and conceding the fact that conversations take their own shape and time (Henderson 2011: 66). Alphonso Lingis writes, “to enter into conversation is to struggle against the noise, the interference, and the vested interests [...]. One enters into conversation in order to become an other for the other” (1994: 87). Ethical modes of engagement are part of practice of bearing witness. The following sections expand upon concepts of witness and ethical writing for this dissertation.

⁷ Cochlear Toxicity which causes hearing loss is a reported side-effect to Streptomycin (Lawrence Flick Memorial TB Clinic 1998: 20).

WRITING WITNESS

In our oldest epics, it is the heroes who are the greatest characters – figures like Odysseus and Gilgamesh and Inanna who battle demons and venture into unknown worlds. But as time passed, the gods and the heroes in stories gave way to ordinary people (Echlin 2010: IX)

This dissertation is centered around many conversations that I had with members from two DR-TB support group sessions, eighteen individual illness-narrative and life-history interviews, discussions with nurses and DR-TB support-group workers, focus-group discussions, creative methodologies and participant-observation. I worked on a daily basis with two female patients, Zodidi and Nombeko, and three male patients, Patrick, Thembi and Lwazi. These patients represent a sample comparable to other patients in their negotiation of side-effects, stigma, ideas about gender and identity related to treatment and illness.⁸ It is through their stories that I have come to understand the particularities and nuances of finding ways to negotiate a balance of the complexities of DR-TB treatment with the demands of everyday life.

In writing this dissertation, I approached it as a narrative based on the stories that patients and nurses shared with me over the course of my fieldwork. Narrative is a methodological convention that allows for explanations and interpretations that reside beyond scientific and medical rationales, offering alternative ways of thinking about, understanding and explaining TB (Boon 2010: 31). Narratives provide important insights on the subjectivities attributed to one disease (Boon 2010: 27-31, 42). The writing process for this dissertation is largely inspired by Abu-Lughod's narrative style of humanistic writing. Subsequent chapters are narrative accounts of the experiences patients and nurses have had with DR-TB. The decision to write the ethnographic data in this form is not purely a stylistic choice but a response to the methodological practices I used throughout my three-and-half months of fieldwork.

⁸ The thematic issues that presented themselves in support group sessions and throughout many conversations were of side-effects, anxiety, suicide, economic stresses, employment issues, strained intimacy and matters of gender and identity related to treatment.

As an anthropologist it almost goes without saying that participant-observation featured strongly in my methodological approach. However, I feel it is more apt to describe the foundation of my work as *witnessing*. The preferential method used throughout the research for this dissertation was bearing witness. Witness is an important stance for research on a public-health issue because it subverts generalizations to allow the idiosyncratic patterns of people's everyday lives to emerge. It requires patience and an awareness of individual modes of speech and expression and an appreciation for the individual character and circumstances described by patients, which are often written and considered as homogeneous experiences amongst patients. The use of bearing witness is a response to the heightened pressure for patients to behave within a strict code of conduct to assist DR-TB infection control. This pressure, imposed on individual patients and their families, juxtaposes patient behaviour as 'adherent' or 'non-compliant' to levels of abstraction that suggest typical characteristics and circumstances, which can suggest or predict certain patient behaviour. This research indicates that even the most biomedically 'adherent' DR-TB patient has either 'paused' their treatment or at the very least considered it. This reveals that patient behaviour, just like any other human behaviour, does not fit neatly into conceptual boxes. Witnessing patients who spanned the various categories of patient characteristics offered me the opportunity to think about adherence and default in new ways.

Witness has a long history in judicial proceedings, but the term has assumed new uses in humanitarian aid and action and testimonial narratives. Currently, international humanitarian organisations often occupy a dual role of providing assistance in addition to "speaking out" or "breaking silence" about the political and social conditions in which they are working (Fassin 2012: 206-211, McKinney 2007: 273-278). According to Fassin,

In the testimony that is brought to the world's awareness, affect is present both as that which bears witness (people's suffering) and as that which is produced by the testimony (the compassion of the public). The truth sought is not the objective truth of the events that occurred, but the subjective truth of the experience of them (2012: 208).

There is a tendency to measure expert opinion against the subjective truth delivered by victims of violence and conflict, a comparison that provokes skepticism toward personal narratives as a legitimate heuristic device. According to Kleinman, “the doctor is expected to decode the untrustworthy story of illness as experience for evidence of that which is considered authentic, disease as biological pathology” (1997: 32). Paul Atkinson maintains that there is an absence in the medical voice presented in illness-narrative accounts, which, according to him, present the world of medicine as “emptied of human, personal content” (2009: 2.4). Medical doctors with anthropological or storytelling training offer a critical contribution, as they can speak to the biomedical community with authority and offer sensitive and nuanced interpretations of patient experiences. For James Orbinski, a humanitarian medical doctor, former president of MSF and co-founder of Dignitas International, wrote an important personal narrative on his relationship to witnessing human suffering. Orbinski wrote, “[i]t is about a way of seeing that requires humility, so that one can recognise the sameness of self in the other. It is about the mutuality that can exist between us, if we so choose” (2008: 4). James Orbinski’s writing demonstrates that there is not only respect for patient narratives in the medical field, but also a need. Bearing witness is an important methodological approach as it creates a space for the “in-between” experiences to act as evidence in medical diagnosis and treatment. In *The Politics of Storytelling* (2002), Michael Jackson oscillates between the personal and the public and asks what aspects of private life are vital to extending to the public consciousness. Writing narrative as part of a humanistic technique to engage with literature and theory is also my ethical response to the many conversations that I was part of or privy to, as well as the creative methods designed and developed with my interlocutors in the field.

ANTHROPOLOGICAL IMPERATIVE

This dissertation is an extension of my honours research, which was conducted in 2010 on the ‘responsibilisation’ of DR-TB patients seeking treatment in a de-centralised facility in Khayelitsha. My masters dissertation was selected as one of the pilot projects for the University of Cape Town’s Knowledge Co-op, whose mandate requires research participants to assist in the design of the research question. Through several conversations with staff from MSF and research participants from my honours work, we agreed that

patient compliance is one of the most pronounced issues that continues to challenge TB treatment and infection control. Ethical clearance for this project was negotiated through several institutional bodies: the Department of Social Anthropology, the University of Cape Town's Faculty of Health Sciences, MSF, and the City of Cape Town's Department of Health. Initially, I wanted to use MSF's network to identify patients who had defaulted on treatment and approach them to be part of my study. As some public-health officials predicted, those who were classified as 'defaulters' declined to participate in my study or dismissed all of my questions around treatment compliance. Approaching only patients who were clinically classified as noncompliant excluded those who were classified as adherent yet could offer valuable insight on treatment-seeking behaviour without anxieties about retribution. I spoke with a range of patients who have paused their treatment, stopped and re-started, or have considered defaulting on many occasions.

I found that patients were often misrepresented in their clinic charts as being absent from treatment when in fact they were present – it was medical personnel who mismanaged patient information. The patients I worked with reveal that a narrow definition of 'default' fails to capture those who experience complex and sensitive challenges throughout their treatment. The research for this dissertation examines variant interpretations of biomedical categories used to describe and prescribe patient treatment-seeking behaviour. The knowledge patients have about their own medical experiences needs to act as credible expertise to reframe how we speak about and address medical care. According to Kleinman, "'subjective' knowledge may sometimes be more valid and useful than 'objective' knowledge" (1997: 78). Medical and public-health expertise function in specific ways, to cure disease, prolong life and protect the greatest amount of people from infection, and clinical categories are established to promote healthy treatment-seeking behaviour. However, what is disregarded within these classifications are the complexities and contradictions that emerge in people's experiences with medication and treatment. Patients often revealed issues or concerns about their treatment experience or symptoms that they would not address with a medical professional because they believed that the condition would not be taken seriously. Patients often suppressed their personal grievances for fear of causing too much trouble or assuming that the matter would not be addressed (Kleinman

1997: 79). The data in this dissertation reveals that matters that are either dismissed or suppressed greatly influence a patient's capacity to remain adherent throughout his or her treatment. I believe that anthropology can offer evidence that can strengthen and support already existing and important public-health strategies.

METHODOLOGY

Developing methodologies in fieldwork is an exercise in trial and error, fuelling a constant awareness of one's positionality in the field. I was conscious of my limitations to perceive the complexities in people's most intimate and vulnerable experiences in such a short period of time. Consequently, I hired Sibuy, a young woman and local resident of Khayelitsha, to act as my research assistant during my fieldwork. She helped navigate complex social and emotional experiences and she tested some of the more creative methodologies we developed with research participants. Sibuy attended all of the support-group sessions and the eighteen illness-narrative interviews I conducted. However, she did not always accompany me when I worked with participants as they expressed feeling more comfortable with fewer people in attendance. Additionally, I hired a University of Cape Town honours student to transcribe and translate all written and verbal material, since Sibuy did not want to revisit many of the conversations we had during research.

Initially I was hosted by two weekly support-group sessions to meet patients seeking treatment through DOTS in Khayelitsha. The support-group sessions were a space where all DR-TB patients from the clinic could go and discuss the challenges they were experiencing with side-effects, stigma, employment and social granting services. Sessions were staffed with MSF peer educators who were also undergoing treatment and were selected based on their compliance to treatment. The sessions took a patient-centered approach with an emphasis on educating patients so they are more informed about their treatment and the health consequences of non-compliance. Patients readily discussed their side-effects and financial concerns during support-group sessions and aired frustrations about nurse-patient relationships. The support-group sessions were held on a weekly basis at each clinic in Khayelitsha that serviced DR-TB patients. As I grew familiar with patients in these sessions it

became easier to develop relationships beyond the clinic space. I met all research participants through these support-group sessions. In addition to the time I spent with my interlocutors, I also conducted eighteen illness-narratives interviews with eight women and ten men from the support-group sessions. I also interviewed five nurses from the clinics where the support-group sessions were held.

I developed different methodologies that addressed affective relationships, encounters, sentiments and spaces that reflected more nuanced concepts of adherence and default. I used a *Language Survey* as way to assess patients' understandings and perceptions of the biomedical classifications of default, adherence, treatment failure, sputum, culture conversion and DR-TB. I administered the language survey at the clinic with patients who were waiting their turn to collect their treatment. Patients often stood as a group and so it was challenging to get individualised responses. Patients shared their answers, asked for one survey for a group to respond, or changed their reactions based on what other patients said. Despite the survey acting as a collaborative dialogue, what was clear was that isiXhosa terms for these classifications differed significantly from biomedical terminology and were often a source of anxiety and confusion. Different ideas of what it means to default came across strongly in the survey, as well as in interviews with isiXhosa-speaking DR-TB patients and nurses. I analyse this data in Chapter 3.

Through discussions held with support-group members I developed four *Focus-Group Discussions* to discern the similarities and differences in treatment-seeking behaviour between men and women. The groups were divided between male and female patients and conducted over the course of several days. These conversations were important as I noticed that the exchanges between men and women in support-group sessions were unbalanced. Women rarely spoke of the intimate challenges they faced while on treatment, while the men in the group dominated the themes brought up in discussions. What emerged in the *Focus-Group Discussions* were matters of sexuality and identity as contributing factors to a patient's ability to adhere to treatment. These *Focus-Group Discussions* enhanced my understandings of the perspectives on gender issues offered by my interlocutors.

The time I spent with patients and some of their family members throughout the course of my fieldwork allowed for more personal and creative methods to emerge. Jointly, we tried different methods to address themes of affectivity in relation to default and adherence. Participants drew family trees to demonstrate where their emotional and/or financial support came from, which family members contributed to stigma, and how family dynamics shifted as a result of their DR-TB. They also indicated that support was not unidirectional, and all participants stated that they had to send a significant portion of their grant money to family members living in the Eastern Cape in addition to helping family and friends in Khayelitsha. The family tree was crucial in developing an understanding of the intricate family dynamics for many patients, and how illness does not exempt one from family responsibilities.

With two female participants we designed *Emotional Maps* that detailed words and emotional reactions that best described their encounters with their community, family members and the clinic staff while on DR-TB treatment. Both participants drew circles that represent the various classifications and included “community, medical staff and family.” Within each ring they noted their emotional experiences related to that categorisation or detailed a chronological account of their illness narrative. Their experiences included negative and positive encounters. This project provided critical insight into the progression of recently developed and familiar relationships related to their diagnosis. They were significant pieces that acted as tools to enrich our conversations or revisit when memories felt unclear. Both Nombeko and Zodidi told me that their maps remain unfinished, as the connection with DR-TB will never cease: it has changed their relationships forever. Although I do not directly analyse the *Emotional Maps* in this dissertation, however, it should be noted that they have shaped many conversations throughout fieldwork and provided rich contextual data about the participants.

view on DR-TB treatment to include also the positive aspects of cure and infection-control. This method is further explained in ethnographic Chapter 4, which details Nombeko's journey.



Figure III: Assembling Collage

CHAPTER III

RESPONDING TO CARE: SHARED VS. CONCEALED PERCEPTIONS OF DEFAULT & ADHERENCE

RHETORIC OF BLAME

Patients often discussed other support-group members who defaulted on their treatment regimen. Rumours about what the defaulter (colloquially known as a “dodger”) was doing animated some members in the group – it shifted the attention from those present to those who were absent. It was often a conversation that grew hostile and incriminating. I remember one session as being particularly impassioned. In attendance was a man who had discontinued his treatment on several occasions and who was back for his third attempt to complete his DR-TB therapy. Everyone in the support group was aware of his treatment-seeking behaviour. Consequently, he was subjected to pointing and wagging fingers and demands to know his reasons for dodging. Patients accused him of being a danger to the community, irresponsible to himself and his family. Throughout it all he remained silent, looking at the ground, listening to the allegations that were entwined with some words of encouragement and support. The group acted out of respect for their community and displayed genuine hope for him to find a way to complete his treatment.

At the end of the session a few members gathered together to discuss the issues that might contribute to default. We were standing in a circle in the sand, and the routine rationales of substance abuse and financial insecurity were discussed as primary factors for absconding from treatment. A break in the conversation prompted a male patient in his mid-forties to grab a stick lying on the ground. In big capital letters he drew “MDR-TB” in the sand, beside it he wrote “XDR”. In small letters to the side he inscribed “tb”. He started running around the circle, theatrically demonstrating that drug susceptible-TB patients are running away from those with DR-TB, yet those with DR-TB are being blamed for the poor behaviour of those with TB. It was agreed that those most likely to “dodge” their treatment and develop poor adherence routines were those with drug susceptible-TB, as they do not know what it means to

have MDR or XDR. The support-group members established that a lack of knowledge about the infection, the length of time required for DR-TB treatment coupled with its profound side effects some of the primary reasons for defaulting. They decided more people needed to be educated about DR-TB in order to reduce the frequency of treatment defaulting. One patient said, “People who do not come for their treatment should be arrested. They infect and kill other people through their negligence.” It was in these moments that I realized how new relationships developed through the support-group sessions, where some members felt responsible for each other and their community as well as reinforcing old ideas about arresting infectious individuals. Some patients wanted to use the opportunity to teach others about DR-TB to reduce stigma and ensure that those who do become infected finish their treatment.

This chapter moves through a series of relationships that were developed, strengthened or disrupted during DR-TB patients’ treatment regimens. Many of the patients that I spoke with mentioned that they had to navigate through new relationships, whether they were recent introductions to medical staff or other patients, or the reorganisation of familial networks as a result of the infection. I am aware that there will be residual effects on most relationships after completing treatment here but this dissertation I will focus on illness episodes. This chapter will look specifically at two different types of relationships: patient-nurse relationships and patient-kin relationships. I show how all those involved in these complex networks hold an overwhelming responsibility to manage the delivery of care and minimise risk of further infection. The instability of patients’ relationships with medical professionals and with close family and friends can have a considerable impact on patients’ adherence. Throughout my research I observed public and private usages of the moral categories of default and adherence. In the support-group sessions, patients expressed moral outrage toward those who absconded from their treatment or who expressed a desire to commit suicide, which was also understood as a form of default. Support-group sessions were often a space where patients passionately discussed other patients’ experiences with adherence to or default from treatment. This behaviour, according to support-group members, was understood to impact directly the welfare of the community. Idioms of blame circulated amongst patients and clinic staff as a way to

understand patients' patterns of default.⁹ These moral engagements reveal how patients are interconnected with their community, clinic staff, family and friends which precipitate new forms of dependent relationships. However, in private conversations with patients the moral categories of default and adherence became increasingly loose, and moral behaviour was carried out with different types of considerations that did not necessarily match the sentiments expressed during public support-group sessions. On the basis of a series of reflections and interactions with patients, their kin and nurses, this analysis will expose the disparity in patients' public and private sentiments and behaviour in relation to default and adherence. The tone behind the categories of default and adherence is that patients have a choice about their treatment-seeking behaviour. This chapter challenges that assumption, showing how treatment-seeking behavior is not a simple decision: adhering to treatment often comes at the cost of something else, either employment, intimacy, or family and personal relationships. Promoting "good" patient adherence ought to address a range of factors that contribute to and influence a patient's capacity to follow strict biomedical prescriptions.

MORAL RESPONSES TO INFECTION

The social, personal and political impact of adherence and default is extensive, so it is also a significant moral issue. DR-TB patients are subjected to moral judgments both from clinic staff, other patients and public-health officials. I apply the term "moral economy" to explain a series of relationships in the lives of those with DR-TB as evidence of noneconomic expectation and obligations that are evoked in the social and political engagements that are not primarily governed by monetary exchange (Arnold 2001: 85). In the context of DR-TB, a reorientation of social and political networks is inevitable: individual and collective action is rearranged to respond to the infection. Attempts are made, through public-health messages, advice given by doctors and nurses and shared experiences with other DR-TB patients, to develop mutual understanding about what constitutes moral behaviour when infected with DR-TB (Arnold 2001: 90). The stories told by patients and nurses throughout this research expose

⁹ Patterns of default were described to me by a nurse who identified some patients as "chronic defaulters" who return to the clinic every few months with the same TB or DR-TB symptoms but never complete their treatment. I also recognise this process when patients modify their medication to minimise side-effects, and adherence and default become contingent on social and familial expectations.

a divergence in opinions rather than a mutual understanding about treatment and illness. Patients' personal evaluations about familial obligations, employment and health are often discordant with public-health messages and drug regimens. The description of the female patient who paused her treatment to take a dress to the Eastern Cape for her daughter is just one of the many examples that demonstrate the disparities in the management of one's illness.

According to Ronald De Sousa, moral behaviour is attached to moral emotions. In this sense moral emotions influence and manage individual moral behaviour and action (De Sousa 2001: 110). Descriptive categories of good (adherent) versus bad (default) patient behaviour are what Michael Herzfeld calls "moral taxonomies" where fellow citizens, public governments, health officials and family evaluate each other based on established ethical criteria (1980: 340). The erasure of exploring what happens in-between treatment and cure or between the home and the clinic reduces patients to typified categories as either morally responsible or irresponsible. A moral discourse on default and adherence assumes there is a rational moral choice for each patient to make when undergoing treatment. It suggests that defaulting behaviour is immoral and therefore punishable either through extreme public-health measures or social chastising. The pronounced moral sentiments that consistently emerged throughout this research were compassion, sympathy, anger and fear. These emotions, according to De Sousa, are moral when they are integrated into a shared impulse for an expected action. Compassion and sympathy can motivate health practitioners to deliver care to the sick, while fear and anger can often give rise to a rhetoric of blame that infers the causes for default. Yet new choices that carry a different formula for moral behaviour can also surface (De Sousa 2001: 118-120). These moral assessments of language and behaviour depict the various possibilities in moral choices that are affected by DR-TB and the treatment regimen.

TO HAVE COMPASSION

Throughout my fieldwork there was an observable tension between the nursing staff and DR-TB patients. During support-group sessions and in private conversations patients claimed

to be treated poorly by nurses¹⁰, accusing them of being abusive and belittling. There were moments during my fieldwork that demonstrated the precariousness of these relationships and indicated that the animosity between some nurses and patients needs to be addressed, both for the sake of patient and for the nurses' continued ability to provide care. Consider the experiences of a female patient in her mid-thirties who, at every support-group session, threatened to abscond from treatment because of her encounters with two particular nurses. For two consecutive weeks her presence at the clinic was not recorded properly on her tick sheet, indicating that she was failing to come for treatment. All of the patients who were at the support group confirmed that they saw her at the clinic every day and others had also been marked as absent when they were actually present.¹¹ Patients said they had little confidence in the management of services of DR-TB care at the clinic. A female patient said:

The nurses are gossiping about me. I was told about my status by a clerk who is not even part of the TB unit. The nurses don't pay attention to the tick sheet. They don't care about their job. They don't look at the tick sheet every day, only on Fridays they try to remember who came and who didn't show. Patients are afraid to complain because it will affect how nurses treat us in the future. This is why patients decide to stay at home. I want to drop my treatment because the clinic doesn't care. You can go to the Eastern Cape and they wouldn't know. What's the point of the tick sheet? They assume you dodge – when you don't, but they don't notice the ones who do. If I stop taking treatment it's the fault of these nurses.

This was not a unique case for many of the DR-TB patients. Lack of professionalism by the nurses was voiced as being a hindrance to the continuity of patient care. Patients and nurses see each other on a daily basis because of the structure of the DOTS programme, which makes it crucial for these relationships to be managed sensitively and respectfully (Chalco et al. 2006: 254). A study conducted on nurses' roles in providing emotional support to DR-TB patients in Lima, Peru revealed that nurses played an integral role in maintaining patient adherence throughout the various phases of treatment (Chalco et al. 2006). Similarly, research in India

¹⁰ Nurses rotate throughout departments in the hospital and clinic care. It is a way to ensure that each nurse is equipped with the skills and expertise to deliver care in different specialties; this is also due to the integration of health services at a community level (Uys & Naidoo 2004).

¹¹ The tick sheet is part of the surveillance technique in the DOTS programme to monitor patient attendance at the clinic. Patients are marked on their clinic cards they carry themselves as well as in their charts that are kept at the clinic.

and Madagascar showed that communication between health-care professionals and their patients significantly influenced patient adherence (Thiam 2007: 385). This places the nurse-patient relationship within a particular ethical-political conversation.

Hostile interactions between nurses and patients were frequent. Patients believed that the nurses did not care about their suffering or their conditions. And yet, a candid conversation with a DR-TB nurse made visible the complexity in delivering treatment in a resource-poor climate for patients with a highly infectious disease.

Nurse: We don't focus on the person the way we were taught in school. You have to write everything down. If you forget to write something down, they will think that you took the medication for yourself. But you forget to write sometimes because you oversee so much.¹² When they [management] have a problem they call you in but they don't understand the conditions we work in. I don't know where all the nurses go after graduation. When you ask them [a patient] if they understand the medication and they say yes, but we don't ask how they understand it or what exactly they understand about it. They might be embarrassed that they are confused or they are lost with too much information, so then you see that person again or the following year. They come back with the same condition. They don't come when they are feeling low, they come when their condition is advanced. They wait until everything stops working.

Laura: What would make your job easier?

Nurse: You know if there is someone at the age of 30, who we could force to be isolated and get him healthy and then send him back to his life. I think that would be a good idea, but you can't do it. When someone is mentally ill they can be put in a hospital, but when someone is just MDR and doesn't believe in their health or is faithless in their medication or their social circumstances, whatever... they will not be committed but they just come back whenever they are sickly. I can't see how that would work.

L: As a nurse what do you experience when you see someone returning with the same condition?

¹² There is a shortage of nurses across the country, along with a steady decline in enrollment in nurse education and training (DoH Western Cape 2010: 1). The shortage increases workloads on nurses that are not necessarily related to their professional skills. Some nurses have expressed having to provide social work services and cleaning duties throughout the clinic and hospital. All of which take away from the quality of services needed for patient care (de Wet & du Plooy 2012: 33).

N: No compassion. You think that these people are a danger to the community. They spread the disease. They still walk and talk in the community and they are putting everyone else at risk. They need to be put in a place without their consent, but I don't know how that could work.

L: You assume risk in your job, and the system doesn't allow you to confine someone, but they require you to serve them repeatedly – how does that make you feel?

N: When you see someone and you see that they don't appreciate it, it takes the compassion away. I think that that is an understatement. You just want that person out of your face. You just give them the medication because you know that they will be back. You don't care if they take the medication in front of you because you know no matter what you say or do that that person will be back. You know that that person can be well, but he isn't committed. So how I can give my 100% when he isn't committed? It's like that. You don't ask why the patient refuses medication – you don't care. Especially males. Males are worse than females.¹³ They don't call you a nurse, they call you names. These patients disappear even when they are sitting in front of you. They disappear when they are still existing, so my love and care are all gone. You try to understand the new ones and then you see them in a system of defaulting. I've seen a guy with TB for four years. When I first started I had compassion and he comes all the time, and when he comes he is very sick. Sicker than most, but I make him wait. There's no point with this one. Death is the only thing that can serve him. It's only death that can heal this one, because someone comes each and every month and you wish they could be committed.

The nurse's articulation of losing compassion for those she treats is not an apathetic reaction to care. More aptly it demonstrates a series of complex entanglements that are present within these connections of care. Nurses working with patients who have DR-TB assume a great deal of risk in their profession. Two other nurses that I interviewed said that if they were given the choice they would not work with patients with infectious diseases. They believe that they ought to be financially compensated for this risk, or at the very least be given a choice as to which unit they would work in the healthcare sector. During my fieldwork a South African national newspaper, *The Mail & Guardian*, published a feature on the occupational hazards that medical staff assume when working with TB patients (Malan 2012). The risks of being a

¹³ Statistical reports in South Africa reveal that women have a higher incidence of DR-TB than men (O'Donnell 2011: 1942). However, of those infected with DR-TB, men are more likely to default on treatment (MRC SA 2002: 31).

medical practitioner in South Africa are situated in the high prevalence of HIV/AIDS throughout the country. Needle-prick injuries put healthcare workers at an increased risk of contracting blood-borne infections. It has been documented that young medical personnel do not report needle-prick injuries for fear of an HIV test or a reprimand from senior staff (Zungu et al. 2008: 48). Beyond fear of stigmatization, medical professionals who do report a needle-prick and begin on a post-exposure prophylaxis regimen often have poor adherence outcomes due to extreme side-effects (Cardo et al. 1997: 198). The clinical reality of TB and DR-TB in South Africa poses professional ethical questions on the “duty to care” because frequent exposure to the infection increases one’s risk of transmission. A bioethical debate on the “duty to care” post-SARS outbreak in Canada in 2003 exposed the conflicting obligations that health-care practitioners encountered during the epidemic: responsibilities to protect oneself, one’s family and the broader community were often at odds with each other (Ruderman et al. 2006: 2). By and large it is accepted that health-care professionals have entered into a moral contract to provide care even when risking personal infection: “There is no other sector of society that can be legitimately expected to fulfill this role and to assume this level of risk” (ibid: 3).

Incriminating discourse places blame on patients or nurses for the management of DR-TB care and infection control. This is not to suggest that nurses and patients are free from responsibilities in managing treatment-seeking behaviour, but the rhetoric of blame distracts from the failings of the bureaucratic responsibilities needed to execute adequate DR-TB care. The truculent relationships between nurses and patients is part of a network of exploitation that systematically exercises violence over vulnerable populations, and its enduring effects sustain a moral economy that rewards or blames on an individual basis (Farmer 2004: 307). DR-TB treatment in a resource-poor setting like Khayelitsha necessitates that provincial and municipal governments engage beyond healthcare service-delivery and address how to improve interventions that directly affect those in healthcare delivery and their relationships with recipients of care (Chipkin 2003: 67). The examples of nurse-patient interactions demonstrate how such tensions operate through various tiers of healthcare delivery, affecting medical professionals and their patients. From the standpoint of DR-TB patients, many nurses assume a moralistic assessment of a patient’s behaviour and treat said individuals through prejudiced

appraisals. Violent utterances like, “You must want to die, you must like being sick,” or “I don’t care, I am not the one who is sick”¹⁴ encourage defeatism in some patients. Beyond the internalised and individual response to such judgments, it also fails to stimulate a respectful and effective rapport between nurse and patient. It was clear that some patients’ attitudes toward nurses were also derogatory and abusive: “Sometimes I see how far I can push them. They wouldn’t be employed without my TB or I am not afraid to shout at them.” Routinely these comments were reactionary to nurses’ attitudes rather than provocative, but nonetheless illustrate the volatile interactions between nurses and patients.

The emotion present in the sentiments held by both nurses and patients directs attention to the affective dimensions of these connections. Emotional expressions such as “loss of compassion” are replete with morality. Moral emotions have been known to influence and trigger certain behaviour. For example, feeling compassion for another may lead one to act to alleviate suffering (De Sousa 2001: 110). From this perspective, it is important to identify common emotional expressions held by those delivering treatment, as these sentiments may have direct impacts on individuals seeking care. This position straddles dangerous territory as nursing is predominantly a female profession, and “irrational” emotions are most commonly gendered as female (Lutz 2008: 78). However, paying particular attention to moral emotions can begin to articulate the connections between idioms of blame and bureaucratic failures and misgivings (Herzfeld 1982: 645). Tracing the etiology of the nurse’s phrase “no compassion” reveals that she lost compassion is a result of specific patient behaviour but also suggests that she is being overworked and misunderstood by her employers. Bureaucratic bodies play a central role in shaping nurse-patient relationships. Overworked nurses who are not adequately compensated sustains a rhetoric of blame and hostility from nurses to patients. Exposing how blame is distributed between nurses and patients aptly demonstrates how “structural violence harvests its victims” (Farmer 2004: 317). It is essential to be conscious of the concepts of structural violence when exploring the capricious sentiments and actions between nurses and patients.

¹⁴ These phrases were pulled from three separate illness narrative interviews.

“I AM ALREADY DEAD”

“We know ourselves in our mortality.”

-Lingis 1994: 159

The social and familial positions of those infected with DR-TB change drastically over the course of treatment. Attitudes about obligations and responsibilities are reorganised from the moment of diagnosis, revealing a state of impermanence in both kinship and social bonds. The nurse’s statement, “they disappear when they are still existing,” is evidence of dispirited sentiments held by some DR-TB patients. Conversations about suicide were not uncommon among many of the research participants. Both explicit and implicit statements of suicidal thoughts suggested a desire to disappear from one’s current condition or to end one’s personal suffering and to alleviate the distress felt to be imposed upon family and friends. The emergence of new dependent connections with medical personnel, and the restructuring of old relationships, can be accompanied by profound emotional distress. The new social position generated as a result of having DR-TB can manifest in expressions of suicide.

Several patients associated DR-TB with a death sentence. Even after being told that DR-TB can be cured, they still associate the illness and its treatment with death. Given the extreme side-effects from medication, some of the participants expressed that the treatment was killing them more than the infection. One illness-narrative interview was conducted the day after a support-group session where it was said that an elderly DR-TB male patient tried to end his life by poisoning himself. The group was angry about his decision and even offended that he was “giving up” so easily. As new forms of dependent relationships emerged between DR-TB patients in the support group, as they embodied a sense of “collective morality” associated with good or bad patient behaviour (Davis 2012: 119). They expected one another to represent an adherent and hopeful disposition to the broader community, articulating that DR-TB can be cured. The support sessions often replicated the tone of public-health messages and reinforced the stratification of adherent and non-adherent patients. This resonates with Patricia Henderson’s work on HIV/AIDS and intimacy. Henderson remarks that public-health messages encourage condom use to limit exposure and risk from infection, however, little has

been written about how individuals living with HIV/AIDS experience intimacy despite the preferred behaviour promoted through public-health messages. The expected behaviour needed for infection control is often at odds with different types of social and personal expectations and experiences (Henderson 2012: 128-129). The idea of collective morality and expected behaviour amongst individuals living with an infectious disease reflects what it means to be a patient in a particular context, and what projected behaviour is desired and at what times. Present in both this ethnographic work as well as Henderson's writings are the inconsistencies and tensions that emerge in private disclosures as opposed to public statements.¹⁵

The day after that support-group session I conducted an interview with a forty-two-year-old male patient, Patrick. The interview revolved around Patrick's reaction to the patient's attempted suicide. He referred to the poison as "medicine" to drink "with good reason." These statements implied a sense of coherence to ending one's life if he or she is infected with DR-TB. He said that he sometimes thought of throwing himself in front of a moving train because he already felt dead. He said, "Because I am nothing. You see. I am alone with this disease. I am alone. I can't ask someone for anything." Patrick applied a certain type of logic to his perceptions of suicide. He saw compounds that had the capacity to end life as healing rather than harmful, alluding to death as the only way to end suffering. This corresponds with the nurse's statement about defaulting patients: "Death is the only thing that can serve him. It's only death that can heal this one." These sentiments challenge the normative biomedical therapeutic practices by offering an escape from DR-TB through death and reveal an atmosphere of despair that is concealed from public statements. Death is understood to have the capacity to heal an individual from an existence of suffering. This sense of logic in suicide was not unique to Patrick's perspective. Another interlocutor, Thembi, a twenty-six-year-old male DR-TB patient, routinely spoke of slipping in and out of suicidal thoughts.

Yoh. You just thinking inside your head, I just want to die now. If I just go now. I don't want to go through the pain and suffering. Sometimes it's like you don't care about yourself.

¹⁵ Elizabeth Davis' perception of "collective morality" is expressed in her view of the hypocrisy that often bounded in the displays of exterior and interior identifications (2012: 119).

The occurrence of suicidal thoughts resonates with the fact that DR-TB comes to dominate one's existence and drastically disrupts one's approach to everyday living. Thembi's domestic encounters portray how DR-TB comes to dominate arrangements in the household. Thembi's perspective on his past and present living conditions demonstrate the profound ruptures that occurred in his life because of DR-TB. He is a single man who was living with his cousin and her three small children. He discussed his unwillingness to disclose his DR-TB, but comfort in telling them that he had drug-susceptible TB. This was a distressing reality on two counts: there is a legitimate public-health concern about infection control, coupled with the fact that he is not receiving sufficient emotional support from his family. The underlying reason for hiding his DR-TB status was his desire to minimise the burden on the household and to ensure he would not be evicted from their home. He imagined disclosing his DR-TB status would lead to his eviction from the home, as a result of which his cousin would no longer receive his financial contributions from his monthly social grant. These conversations did not necessarily capture the type of relationship that Thembi shared with family prior to his DR-TB diagnosis. They do, however, provide evidence on the dynamic functions of familial relationships. Thembi's decision to keep his DR-TB a secret can be read as an expression of "fear" from a threat that may result from his disclosure. Brian Massumi wrote about the affective nature of threat, where anticipating threat creates the imagination of a fictional reality that may be worse than one's present (2010: 54). These feelings erupt in a moral and ethical deliberation on the personal and social implications for sharing one's diagnosis and the possibility of ending one's life rather than continuing with treatment.

Thembi's relationship with DR-TB began long before it was detected in his lungs. He shared a room in his cousin's house with his cousin's brother-in-law who was "dodging" his DR-TB treatment. The two men bunked together for eleven months before the brother-in-law died. Several months later Thembi was diagnosed with DR-TB. Thembi recalled observing how his roommate avoided telling other members in the household about his infection and how he openly refused to take treatment because, according to Thembi, he felt worse from the pills. Thembi admitted that witnessing someone else "dodge" his treatment influenced his own behaviour and attitude toward the treatment. Thembi struggled throughout his treatment to remain adherent and as a result he was in and out of the hospital during the first three months

of his treatment. His family knew that he was in the hospital, but nobody came to visit. Tembi's connections with his kin were a contentious topic of conversation: he frequently ended discussions abruptly or ignored my questions altogether. When I asked if he thought he should tell his cousin to get her children tested for DR-TB, he replied,¹⁶

She doesn't know that I've got MDR. She thinks its normal TB. I don't need to tell her anything. It's like she'll judge me. It's the BIG BIG BIG TB that I've got. People are scared, even me I'm scared. So... that's why I don't tell. It's like that.

The portrayals of Patrick and Thembi suggest that suicide is a topic beyond support-group discussions. Those infected with DR-TB constantly evaluate what they can lose if they admit to being infected with DR-TB. These fears are symbolic of “self-presentation and self-concealment” where the expectation of the group is founded on a “collective morality” that is often at odds with the internalised sentiments of distress (Davis 2012: 122). Stigma is pervasive in conversations about TB, DR-TB and HIV. Kate Abney's master's dissertation on stigma and DR-TB exposed how stigma reshapes and disrupts social and familial relations on varying scales (Abney 2011). Fear of losing one's livelihood, housing, marriage or children are often raised when addressing the topic of disclosure. Stigma and DR-TB are not isolated from comparable distresses about HIV testing and disclosure. Many individuals have declined an HIV test due to discrimination, fears that medical records will not be kept confidential, changes in sexual relationships and fears of social exclusion (Bell et al. 2007: 117).

PERFORMING CARE

Family and friends play an important role in helping patients through their DR-TB treatment regimen (Winterton 2010). There is no denying that DR-TB disrupts and rearranges intimate bonds, and the accounts offered by Patrick and Thembi indicate the importance of sustaining connections that will help patients move through their suicidal thoughts and despondent emotions. Those patients who have supportive kin still expressed suicidal thoughts at some point during their illness, but they were able to manage them much more easily.

¹⁶ Perhaps Thembi did not feel as though he needed to tell his cousin his DR-TB status because everyone in the household had already been exposed to the infection prior to his diagnosis. However, when I asked about questions of guilt or concern of infecting others he avoided giving me a response.

During one of the male focus-group discussions, a respondent said that after he received his DR-TB diagnosis he wanted to hang himself: “I contemplated using the rope I had at home to hang myself because I did not really know much about it [DR-TB] and I thought that I would die.” He waited two days before telling his wife about his status, after she recognised his distress. He told her that he wanted to hang himself. She encouraged him to go to the clinic and take treatment, because she knew that DR-TB could be cured. He said that he had not understood that the infection was curable. This comment resonates with the description offered at the beginning of this chapter, where the support-group members felt they lacked adequate information and said they believed that this contributes to defaulting behaviour. Lack of information or understanding about the infection influences some patients to associate the infection with a “death sentence.” Equally, patients expressed that those with TB do not take the infection seriously enough. In an interview with a nurse, she expressed that patients who are diagnosed with TB are not told of the possibility of developing or contracting DR-TB:

You tell people that they have TB but when you tell them that they have become MDR because they didn't take their treatment last time¹⁷ it always comes as a shock. It's always the first time that they have heard about MDR or XDR. They are not being told about MDR or XDR and that it can be cured. Nobody ever says that they understand. They think that they are going to die. I think that it should be like the HIV campaigns, even though people are still careless, but at least people know. You would still have carelessness about it, but at least they would have more knowledge about it. They die not understanding what they have.

Nurses and patients both acknowledge that a lack of information about the progression of the TB infection and its curability is missing in broad public-health campaigns and in conversations between medical personnel and their patients. A male patient once told me that the details about DR-TB are reserved for those who actually contract it.

Family and community members also need to understand the characteristic of DR-TB in order to offer support and facilitate infection control in their own homes. Zodidi, a diabetic in her mid-forties, left her husband and three children in the Eastern Cape after being diagnosed

¹⁷ Some cases are not a result of treatment adherence so the nurse could be blaming patients unfairly.

with DR-TB. She moved in with her younger sister to undergo treatment in Khayelitsha. I met Zodidi a month before she was discharged from the clinic and given a clean bill of health. Her sister accompanied her to all of our interviews, as they wanted to spend as much time together as possible before Zodidi moved back to the Eastern Cape to rejoin her family after being separated for over two years. Zodidi's sister, Precious, reflected on the challenges that she encountered in providing care to someone with DR-TB while trying to look after her own family.¹⁸

Precious: I have my own child. My problem at first was that I was wondering what was happening with the people she left in the Eastern Cape. She was very sick, and she used to visit our mother, and her small child. Also, what would my husband's family say if he got sick because of my sister? But my husband supported me. We got through it. Even in the times when she was thinking of suicide. I wondered every morning if she would be gone.

Zodidi: [interrupts] I was always negative ever since I started treatment.

Precious: I used to ask, "Do you want to be cured?" Because she used to always think about suicide. I would wonder if that's it, when I left the house. That would be what she wanted. I always tell her that I love her and that I want her in my life. [...] So we managed because I want her in my life. Her kids are still waiting for her, her mother is waiting for her, and her husband is waiting for her.

Precious worked as a nurse before Zodidi's DR-TB diagnosis. However, she had to give up her shifts in order to stay and care for her sister. Precious confirmed that there is a great deal of tension between nurses and patients, and therefore reiterated the importance of family support systems when receiving any sort of medical treatment.¹⁹ According to Precious, without family support patients are likely to take their treatment improperly or stop altogether. Precious' household was financially strained, which forced her to approach their other siblings for assistance. Her two older brothers refused to help, which created a profound rupture in the family. This was made clear when we were drawing their family tree – Precious left the room and said she could not participate because she could not forgive her brothers for abandoning

¹⁸ Zodidi's sister had a husband and a four-year-old daughter. Zodidi's niece had been put on prophylaxis to ensure that she did not acquire the infection.

¹⁹ On Zodidi's emotional map she wrote that the way in which nurses treat patients is a primary cause for default.

them when they needed them most. Surprisingly, Zodidi and her brothers have managed to repair their relationship with one another once she completed treatment. Precious said that that reparation was only possible because Zodidi was unaware of the abhorrent reactions of her brothers, because she protected her from them.

Zodidi's relationship with her sister was crucial in several ways: Precious encouraged her to remain adherent throughout the course of treatment and assisted her during periods of suicidal inclinations. Precious sacrificed her relationships with her brothers in order to maintain the connections for her sister. Families and communities are entrusted to take on practices of healthcare for those who fall sick. Yet, the experiences of relations providing care as a result of this expectation are often understated (Henderson 2012: 154). New relationships of dependency restructure family dynamics and community ties.

MIGRATING FOR HEALTH

After doing some of her own research, Zodidi went to her local clinic in the Eastern Cape in January 2010 to be tested for TB. An x-ray revealed that her lungs were clear and she was sent home. Despite a negative diagnosis, her illness progressed: night sweats, weight loss and profound fatigue became part of her constitution. In March 2010 she went to East London for more tests, where it was discovered that she had TB. She brought her referral letter back to her local doctor who wanted another x-ray to confirm the diagnosis. She did another chest x-ray but was not notified of its results and was asked to produce a sputum sample. She knew the sputum sample would take a few weeks to be analysed and was suspicious that a result would actually be given, since she was still waiting to hear of the outcome from her chest x-ray. Consequently, she decided to seek assistance elsewhere. Months of inadequate care from her local physician and clinic motivated Zodidi to move to Khayelitsha to receive her TB treatment. After several months of TB treatment in Khayelitsha, Zodidi was informed that she had developed DR-TB. She was devastated, for what she thought would be a six-month sojourn in Khayelitsha turned into a minimum of two years. Although she was separated from

her husband and children, Zodidi firmly believed that she could not get the care she needed in the Eastern Cape.

Discussions about migration patterns between the Eastern Cape and Cape Town surfaced continuously throughout my fieldwork. Migration to Cape Town from rural areas in the Eastern Cape has a long and complex history. The most prominent reason for rural-to-urban migration is the search for better employment opportunities or reunion with family. The rural-urban nexus in South Africa is in constant transition, households are understood to be ‘stretched’ across space as family members are dispersed yet hold an obligation to provide subsistence to their rural homesteads (Ndegwa et al. 2006: 224, Pick & Cooper 1997: 47, Spiegel & Mehlwana 1997: 17). Economic reasons aside, there is a strong connection between health and migration, and the HIV epidemic in South Africa has generated significant attention to issues on circular labour-migration and health throughout the country. It was noted that men living on their own in urban settlements for employment and who contracted HIV often brought the infection back their households in rural areas when they visited their families (Clark et al. 2007). The elements of TB transmission and migration are embedded throughout networks that span across the country, as patients continue to move between geographical spaces. Several of the patients that I spoke with wanted to return to their rural areas to complete treatment, because being around family felt more therapeutic than the biomedical treatment regimen they were receiving in Cape Town. This differs from Zodidi’s circumstance, which was also shared by others who indicated that they moved to Khayelitsha in order to obtain quality healthcare services (Ndegwa 2006: 227).

I take these conversations about urban migration for healthcare services as yet another example of the deficiencies in medical care across the country. There is an increasing amount of literature on the benefits of urban living for female reproductive health in South Africa, such as increased access to pap smears, screening for cervical cancer, antenatal care and birth control (Byass 2010, Pick & Cooper 1997). This reality can be extended to general healthcare services for both men and women. Zodidi’s choice to move to Khayelitsha was not related to her reproductive health but was a reaction to her experiences of ineffective healthcare delivery at her rural clinic. This case resonates with difficult moral choices that individual patients and

families must make when coping with DR-TB. Zodidi's loyalty to her family along with her own personal health persuaded her to separate from them and seek care where health resources were less scarce. In one of our last conversations Zodidi said:

Only God knows what will happen. I need to write a book about what happened to me. I need to tell my child why I had to leave them. It was for my family. Even though I lost hope, I said, God, please just do this for me. I asked God to let me go home on my own two feet, not lying on my back.

The above comment expresses Zodidi's anxiety about dying before having the opportunity to explain why she had to leave to her children. As Zodidi's story unfolded, I realised the profound role that Precious played in keeping her sister alive and on treatment. Zodidi's decision illustrates the extreme choices that patients have to make when seeking treatment in a resource-poor setting. At the same time, the distrust that her rural physician exhibited in her diagnosis from East London indicates mismanagement of resources, rather than a lack thereof.

CONCLUDING COMMENTS

In working through the various networks of relatedness in connection to DR-TB treatment, I observed a discrepancy between private and public sentiments of default and adherence. Patients expressed certain moral sentiments about suicide, default and adherence through public-health-speak in spaces like support-group sessions. However, private conversations about the same topics elucidated very different reactions. Suicide and default carried divergent meanings. Suicide was expressed as a form of healing or escape, where default is part of the rhetoric of blame that revolves around bureaucratic and personal failings to act in a morally correct manner in the context of DR-TB treatment. The emergence of new dependent relationships with medical personnel and family reorganises and disrupts family and community structures, and this disruption can have deleterious effects on the ways in which individuals come to access and sustain care. This chapter revealed that the management of relationships between health-care providers, patients and family members is a critical aspect in understanding default and adherence patterns in DR-TB patients.

CHAPTER IV

“EATING TREATMENT” AND SPLITTING PILLS: RESPONDING TO CHANGE



Figure IV: Clinic

PILLS & RITUALS

During the weekly support-group sessions I was intrigued as I watched the rituals²⁰ patients embodied when swallowing their DR-TB medication. Some young men prepared their bodies for a physical fight, rolling their shoulders back and forth while jumping up and down on one spot, and they would end the ritual by cracking their fingers and their neck before throwing all of pills into their mouth. Some of the women would find a place between two parked cars in the parking lot to swallow their medication at their own pace and in privacy.

²⁰ I applied the term ritual with the understanding that patients invariably carry out a series of specific actions when they swallow their medication. In observing the same patients on a daily basis throughout the course of three-and-half months, I noticed that many patients performed the same ritual before and after swallowing their prescribed medication (Farquhar 2007: 69-70).

Others stood around the tap a few meters from the support-group circle and helped each other to hold a cup of water or in placing the pills in their fellow patient's palm before they ingested the medication. Nombeko was never hurried in her ritual. She would sit slumped, grimacing at the plastic bag full of pills for several minutes, until she placed as many in her mouth as she could. She never took more than three pills at a time and she always swallowed them while pinching her nose to demonstrate her repulsion. She would swing her hands by her sides in a manner that looked as though she was propelling the pills down her throat.

The practice of taking DR-TB medication for the prescribed period of eighteen to twenty-four months is an undeniable disruption of one's everyday life. In order to understand how DR-TB patients respond to and interpret this interruption, this chapter will trace the life history of one female patient, Nombeko. Nombeko's narrative captures the layers of side-effects that surface throughout treatment and infection. The ethnographic data will reveal how side-effects are stratified across various aspects of a patient's life and influence the physical, interpersonal and individual realms of the patient's existence. Through a paired examination of the physical and emotional side-effects that emerge throughout treatment, this chapter will describe how side-effects move through various states that generate a sense of contradiction. I will illustrate how some of the contradictions define Nombeko's treatment experiences as distinctly female, which have shifted her sense of identity to the extent of being unrecognisable to herself. This detailed patient perspective on the layers of affective conditions that can manifest themselves throughout the course of infection and treatment demonstrates the evolving transformations that can occur beyond the corporeal self, and which trespass into the invisible realms of the psyche, when living with DR-TB.

The transgressive nature of side-effects of DR-TB treatment assumes paradoxical properties for many patients: its physical and emotional side-effects run parallel with elements of healing and cure. For Nombeko, this reality yields a sense of contradiction in her experiences of the infection and its treatment. Related to this contradiction, I observed a practice of what Steven Brown and Ian Tucker call "tailored adherence" which is self-modification of one's drug regimen to experiment with such side-effects (2010: 229). Although this is categorically considered defaulting behaviour, the ethnographic material

demonstrates that it is a process of self-preservation and a coping strategy to maintain a sense of control over one's own body. In what follows, I will examine a series of events in Nombeko's experiences with DR-TB that reveal some of the emotional underpinnings that contributed to her perceptions of her transient sense of identity that have challenged her ability to remain strictly adherent to treatment. It is critical to address such issues in public-health campaigns and strategies as a way to include matters of identity and gender politics that address the visible signs of a "disintegrating body"²¹ or the notable changes in female reproductive health. A restructuring of public-health support services that includes such profound issues could help patients to develop more meaningful and diverse coping strategies during their treatment and after cure.

BEYOND CATEGORIES

Pamela Naidoo and Kelvin Mwaba conducted a study on helplessness and depression in people being treated for TB in a Cape Metropole in South Africa. Their study revealed a high tendency to depression among TB patients, so they advocate for more psychosocial support (Naidoo & Mwaba 2010: 1331). There have been several studies on patients' sense of helplessness, depression or psychological side-effects in relation to their inclination to adhere to treatment (Muture et al. 2011, Naidoo 2009). However, the studies often read as a generalised account of psychological effects with little identification of the various subtler forms of psychological distresses that can emerge throughout a patient's treatment. Additionally, there is a dearth of literature and research that documents the psychosomatic aftermath of being on treatment for DR-TB. An analysis of this nature may reveal why re-treatment patients have a higher propensity to default in their current drug therapy. Patients' psychological health is an extremely important factor in DR-TB treatment management and more attention must be paid to the heterogeneous nature of psychological distress in DR-TB patients in order to address such complex issues. Understanding how DR-TB treatment disturbs a patient's sense of identity will present more nuanced aspects of distress throughout the illness. According to Didier Fassin and Estelle d'Halluin:

²¹ A male patient in his late twenties expressed extreme anxiety over his appearance of a "disintegrating body" which he feels is emasculating to project a weak and vulnerable body.

The body brings proof through its materiality, [and] the psyche only exists through the patient's words and through the specialist's categories. [...] Clinical vagueness facilitates translating a personal conviction into a psychiatric diagnosis that will provide evidence for the administration (2007: 319).

Fassin and d'Halluin point to the complexities in managing psychological symptoms that require substantial amounts of time to bear witness to the individualised manifestations of conditions that are not neatly ordered into broad psychiatric categories. The intention is to expand upon conversations on how certain emotional suffering emerges during patients' experiences with their infection and their treatment.

MEETING NOMBEKO

I met Nombeko in February 2012, three weeks after she was diagnosed with HIV and DR-TB. She lives with her mother and sister approximately five kilometers from the clinic where she receives her treatment. The home belonged to her father who died of TB in 2008, the same year that Nombeko was reunited with her parents. Nombeko's parents left her and her five siblings in Transkei in the Eastern Cape province of South Africa with their paternal grandmother while they searched for better employment opportunities in Cape Town. Nombeko recalled that in the seventeen years of being separated from her parents they never sent money home, nor did they visit or call. After dropping out of secondary school at age sixteen for financial reasons, Nombeko left her family and sought work in Johannesburg. There she met her father's brother, who invited her to live with his family. In the year she spent with her uncle she felt like a "second-class citizen" and not wholeheartedly welcome. At seventeen she traveled to Port Elizabeth, one of the largest cities in the Eastern Cape, where she stayed with a friend and found work as a char. Nombeko said that this was the point when she realised that she was on her way to find her parents. However, her time in Port Elizabeth was extended after her Muslim boyfriend impregnated her. In 2006, Nombeko gave birth to identical twin boys. She spoke lovingly and respectfully of her children's father and his family. They embraced her, invited her into their home and ensured that she and the boys received quality medical attention. This period was one of impermanence for Nombeko, for as she became more intertwined with the family they expected the new parents to marry and that

Nombeko would eventually convert to Islam. Both Nombeko and her partner were insecure about these commitments, and although they respected each other, they never wished to spend their lives together.

Nombeko admitted that if she had stayed in Port Elizabeth her life would have taken a very different direction. She wonders if she would be HIV-negative and still oblivious to the realities of DR-TB. Despite her retrospective curiosities about what her life could have been, she was clear and remains so in her decision *not* to convert to Islam or marry a man out of custom and obligation. In 2008 she left the twins with their father and his family with the agreement that he would have full custody, and she could visit and maintain open communication with her sons. This arrangement worked for many years: he would pay for Nombeko's ticket to Port Elizabeth so she could spend a week with the family. The children are growing up Muslim and speaking Afrikaans, so Nombeko feels increasingly estranged from them. Their father married a Muslim woman, whom Nombeko says is a wonderful mother to her sons. However, 2012 was the first year that Nombeko was unable to go to Port Elizabeth on Easter because of her treatment regimen. Her sons' father has interpreted this as a disinterest in their children and has requested she sign legal documentation to allow his wife to legally adopt the twins. Nombeko said that this will be yet another thing that DR-TB and HIV will take away from her.

Nombeko's journey to Khayelitsha in 2008 was motivated, above all else, by finding her parents. She arrived in Khayelitsha without any way of contacting them and spent her nights sleeping in petrol stations and her days inquiring about their whereabouts with whomever would listen. After a week of searching, she arrived at her father's house early in the morning. Her surprised but overjoyed father embraced her, which was a deep contrast to her mother's hateful reaction: "You should have stayed where I left you." Nombeko moved in with her father, who lived on his own, since her parents had separated after her mother conceived a child with another man. Nombeko never had the opportunity to get to know her father, ask him why he left or did not return, since upon her arrival he was already extremely ill. It was only through her father's illness that Nombeko developed any sort of relationship with her mother, who would come to check on him occasionally and want to know why he was not taking his

TB medication. Nombeko recalled the day he went to the clinic for a checkup and never returned. Nombeko's mother blames her for his death and also for her own symbolic passing: Nombeko's birth represented a symbolic death for her mother, as she felt trapped in a loveless marriage and had to give up her opportunity to pursue more education. Her mother routinely told Nombeko that she was the only child whom she does not like: she has always wanted to "bury her when she was born" and continues to carry that feeling today. Nombeko's birth marked an end for her mother, as Nombeko was the firstborn in what she claimed to have been a loveless marriage. With enduring hostility, they now live together under her father's roof and Nombeko's mother is convinced that she got sick to provoke her. By shifting between different locations and negotiating new and tenuous relationships, Nombeko has structured and restructured her sense of identity in relation to these evolving contexts.

PILL BURDEN: THE CHALLENGES OF CO-INFECTION

In South Africa, TB and HIV services are integrated as a way to address some of the complex issues that emerge in the delivery of treatment to co-infected patients (SADoH 2010: 13). An integrated strategy is recommended as a way to encourage adherence to both treatment regimens, increase patients' understanding of the co-infection, and monitor signs and symptoms of drug toxicity (Scano et al. 2008: 1371). Drug toxicity is a significant problem in concomitant HIV and DR-TB drug therapies that present new afflictions that need to be addressed. Some of the clinically significant outcomes of combined therapy include peripheral neuropathy, cutaneous reactions, neuropsychiatric effects, gastrointestinal effects, renal toxicity, bone-marrow suppression, psychosis, nephrotoxicity and depression, to name a few (Pepper 2007: 982, Scano 2008: 1372). Episodes of psychosis, neuropsychiatric effects and depression are some of the most common reasons why patients default on treatment or turn to substance abuse as a coping mechanism. It is also noted that loss of appetite or anorexia is one of the adverse effects. With anorexia or undernourishment, amenorrhea becomes likely for some women (Chan & Iseman 2002: 1283). The majority of DR-TB research and resources is concentrated on developing rapid-diagnostic tests and increasing laboratory support and on developing new medication (Cobelens 2008: 1039). Although these are leading elements for infection control, more emphasis is needed on the psychological components of the disease

that are often directly related to side-effects of the medication itself. Studies on default and adherence are often conducted to predict patient adherence through patient-behaviour characteristics, socioeconomic status, substance abuse and side-effects, while often disregarding the impact of the psychological side-effects of the medication or the infection itself (Kliiman & Altraja 2009, SA MRC 2002, Sumartolo 1993).

Through Nombeko's explanations it became clear that undergoing treatment for DR-TB was a state of contradiction: Nombeko said the medication made her feel worse than the DR-TB did. Through a series of experimentation, where she did not take her ARVs for a couple of days in order to establish which treatment carried more severe side-effects, she determined that DR-TB drugs elicited more extreme side-effects. Providing combined treatment is profoundly delicate for health-care professionals as drug toxicity is well documented in pharmacological literature on the co-management of HIV and DR-TB. For many HIV and DR-TB co-infected patients there is risk of a range of extreme and long-lasting side-effects that may arise due to drug toxicities (Pepper 2007, Scano 2008).

In referring to the literature in a South African context, one must be cognisant of the HIV/AIDS-denialism era that marks the one of the most controversial disasters that occurred during the leadership of the second democratic president, Thabo Mbeki. Mbeki established a President's AIDS Advisory Council, which included many members who publicly discredited the efficacy of ARVs and questioned the fact that HIV causes AIDS. The period known as AIDS denialism, a period in which ARVs were described as 'toxic', has left a residue in people's imaginations and practices (Koenig 2006, Robins 2004). This section will re-frame the term "toxic" as it was an adjective that was frequently used by Nombeko when she described what she imagined the medication was doing to her body. She felt as though her body was becoming a "toxic site." Moreover, pharmacological research emphasises the risks of drug toxicity in co-infected patients. It is through these perspectives, and not an AIDS-denialist one, that the term "toxic" is employed throughout this section. It is important to note that Nombeko was not contesting the effectiveness of the DR-TB treatment itself but expressed strong anxieties about the aftereffects of the medication and the challenges of managing her side-effects.

The management of combined HIV and DR-TB treatment posits many challenges. Some patients in the support-group sessions admitted to “pausing” or “taking a break” from their ARV treatment whilst on DR-TB therapy, or vice versa. This was done either out of concern for contraindication or because they felt as though it was “too many pills to swallow,” or they forgot to take all of the prescribed medication altogether. In one support-group session the peer educators confronted a male patient after they learned that he had been defaulting on his ARVs for the past month.

Peer Educator: You have defaulted on your ARVs. Do you have your ARVs now?

Patient: I do not know at all then what had happened. I cannot read. But I do get my ARVs.

Peer Educator: So where do you get them from?

Patient: Here at the clinic.

[The peer educator went to ask a nurse to come and speak to the group for clarification.]

Nurse: I will not remember whether I gave him his tablets or not because I see a lot of people. The folder is meant to say if he came and if it does not reflect that then it means he did not come to fetch his medication.

The above passage reflects the ongoing challenges between nurses and patients as described in the previous chapter, but it is also emblematic of how confusing it can be to manage combined-drug therapies. Patients often said that they thought they could stop taking their ARVs while on DR-TB treatment and resume their HIV therapy once they completed their DR-TB treatment. The patient mentioned above was confused about the combined treatment as he could not read his clinic card. Peer educators frequently had to remind patients that it was essential to take both treatments simultaneously. Adherence to ARV treatment is essential in order to strengthen one’s immune system to have effects on DR-TB infection (Pepper et al. 2007: 981). The high pill burden for DR-TB and HIV treatment has a profound impact on a patient’s capacity to remain adherent to both drug regimens. Below is an interview with a male

DR-TB- and HIV-infected patient who reiterated the complexities that surface due to the high pill burden with co-infection.

Laura: You said that you were just taking ARVs and stopped with your MDR-TB treatment? Can you explain why?

Patient: Yes, when I started taking the ARVs I focused on taking them and I just forgot about the MDR treatment.

Laura: But your chart indicates that you come to the clinic every day.

Patient: I don't swallow pills at the clinic so I take my pills home. Then I forget. They are both easy to take but the only problem is that I forget to take the MDR medication and sometimes I even repeat my medication and I forget that I had taken my dose for the day. I think the bad memory is from the TB tablets.

Nombeko and Abdi, a Somali refugee from Mogadishu, asserted that they “lost their minds” for a period of time. Nombeko described it as feeling like a “dummy-dummy” where she would struggle to follow conversations or forget the topic entirely. Despite this side-effect that was expressed by patients, they all said that they refused to discuss this with their healthcare providers. Nombeko did not address it because she did not think she would be taken seriously, and Abdi, who recently arrived in Cape Town, did not have the confidence or language to speak with his physician.

EVALUATING TREATMENT: A TAILORED THERAPY

The material act of taking medication appears a straightforward practice with prescribed routines and diets to follow throughout the course of one's treatment. However, taking DR-TB medication is highly complex for both healthcare workers and their patients. From the medical practitioners, a routine and careful tailoring of medication is essential to ensure that patients receive an effective remedy for their strain of DR-TB. Patients who have to present themselves at the clinic every day to receive their pills and/or injections often give-up their employment and have to reorganise sleeping arrangements in already crowded houses. Most patients articulated that their previous and familiar everyday routines have disappeared and have had to

restructure their days to accommodate treatment. Beyond the actual act of swallowing pills, patients discussed the multitude of physical side-effects that were often described as worse than the TB itself. It seemed as though patients used the support group to reassure one another that the side-effects were common and would eventually pass, yet they did not use the space to discuss the more extreme consequences of treatment. Patients' public assertions on the correspondence between the physiological side-effects and their emotional responses were rarely broached in support-group discussions. Customarily they offered each other remedies and advice on managing the physical side-effects. Patients did not address the extreme emotional distress in support-group sessions, but often engaged with such issues outside the structured session. Patients often self-segregated into small groups of men and women while they waited for roll call to receive their daily dosage. It was in these moments when they shared their more intimate and emotional reactions to the medication and the infection, as well as the ruptures that had surfaced in their relationships. The irony is that support-group sessions are supposed to act as safe and private spaces, yet they were frequently perceived as part of the public sphere.

One of the support-group sessions I attended hosted over thirty patients on any given week, a seemingly daunting and impersonal space to address highly sensitive and personal matters. Worried that a passerby would overhear support-group discussions, Nombeko told me that she never felt comfortable articulating the intimate and complex details of her infection in such a public setting. However, in the comfort of her own home, she shared her emotional reactions to the pills: how their smells affected her, how their size was difficult to swallow and how their unpleasant taste suppressed her hunger. If Nombeko could redesign DR-TB medication, she said that she would develop a liquid serum that tastes like vanilla. One of our conversations occurred after we walked to her home from the clinic. She had just received her daily injection and she winced as she rubbed the injection site while we walked. As soon as we arrived at her house she collapsed on the couch and closed her eyes to explain:

Nombeko: It's not easy to know that your life is going to revolve around pills [laughs]. Seriously. All medicine all the time, still there is no guarantee. Just like electricity can go off any time. That's how I feel like I am living. It's not permanent, it's like that. Nothing about this is normal [sighs]. You know these

pills can take a whole day to digest, they can even take until tomorrow, or when you have to put more in your body. You know they changed the colour of my pee? Ha! I've got an orange pee, very, very, very orange. It's not even orange, it's red! It smells – my pee smells like these pills. The first time my pee changed colour I thought it was blood. It made me nervous. To pee blood, you must know that that's a bad thing.²²

Laura: Is this something you discuss with other patients or your doctor?

Nombeko: Nah. I just wonder if the guys who make and give these pills know what it's actually like. They should have to drink them. You know, most people can't take pills. My mother breaks a Panadol [an over-the-counter pain-relief tablet] and struggles to swallow the half. I sometimes break my pills, even though I was told it's like opening a coke and all of the fizz escapes. I also sometimes save the pills from the clinic to take at home at a later time.²³ I know this isn't the right way.

Nombeko frequently alluded to the physical side-effects of the medication, and over several months our conversation evolved to include her affective states that were either a condition of the treatment regimen itself, or coming to terms with having DR-TB and HIV.

Nombeko: I don't know how to explain this... I don't feel myself. I feel crazy. I feel very dumb. Seriously, like a dummy-dummy. I don't know if I want to talk about it. Most people don't talk about it. These pills are making you very, very dumb, and sometimes I can't remember anything. The mind goes for some minutes. I want to know what is happening [she starts to cry]. The doctor even laughed at me when I told her. Maybe she thought I was joking. You know your body. You know when you are not yourself. I don't know why it is so hard for doctors and nurses to understand this. I know it is this medicine.

The routines and rituals that Nombeko and other patients developed with their DR-TB pills were characteristic of Brown and Tucker's (2010) concept of "tailored adherence." Nombeko said that she occasionally split her pills in half to make them easier to swallow, or at times she saved them to take later as a way to avoid symptoms such as nausea or fatigue. Abdi offered a

²² Rifampin, one anti-TB drugs has been known to change the colour of one's urine and a red-orange colour (Addington 1979: 783).

²³ Some patients explained that within the DOTS system they would sometimes be given permission from a nurse to take their medication at home in the event that they were feeling too nauseous or dizzy at the clinic, or they would hide the pills in their pockets or between their fingers and bring them home.

similar description about his routines in modifying his treatment. Abdi worked in a shop run by other Somalis and explained that he could not afford to be tired as he had to work in the shop in order to earn an income for his housing and food. Abdi said he often split some of his pills because he became confused and dizzy, and through a process of experimentation through modifying the amount or size of the pills he took at once he said that he was able to alleviate some of the immediate side-effects. Both patients were aware that their actions could possibly reduce the efficacy of the pills, but this did not deter them from adjusting their treatment as a way to salvage a sense of control over their own bodies.

The practice of “tailored adherence” is a somatic response to specific affective and physical conditions produced by the treatment and illness. Patients who deviate from their prescribed treatment regimen consider their physical and emotional responses to the pharmacological therapies and employ their own routines when taking medication as ways to experiment with side-effects and the changes in their body (Brown & Tucker 2010: 244-247). The act of taking pills is a material experience that is distinct to each individual ingesting medication and often, through careful evaluations, patients may engage in a process of modification as a way of coping with the adverse side-effects. Discussions about medication cannot be separated from the emotional transitions that accompany them. For Nombeko, the realisation that her life was now going to “revolve around pills” was laden with anxiety. The investment of taking medication for two years without a guarantee of being cured is connected with Nombeko’s sense of insecurity and distrust in the efficacy of the medication. Despite her concern about her DR-TB medication, Nombeko was also taking ARVs, yet she did not have the same expectation or suspicion of this treatment, even though she began both regimens around the same time. Nombeko said that she accepted that ARVs would not offer a cure, but would allow her to live a healthy life, but she could not come to terms with the disruptions and side-effects that the DR-TB treatment produced.

IN SEARCH OF EVIDENCE



Figure V: Assembling Collage II

Nombeko's relationship to her DR-TB treatment regimen was layered with complex emotions. The complexity of Nombeko's relationship to her DR-TB treatment was exacerbated due to the recent experience of losing her father to TB. Nombeko moved in with her father who was already suffering with TB. She was unaware of the seriousness of his condition, even though her mother came over occasionally to see if he was "eating his treatment." Nombeko explained:

We were unaware of the dangers of TB at that time. I think he was even coughing blood. He would be coughing and at the same time holding his cigarette. I don't know if he finished treatment or if he tried. He got really sick one day and went to the hospital and never came home. I can say that he did infect me. We were staying in the same room and my mother was sleeping

somewhere else. He never sat me down to say, "Listen, my daughter," he never did.

Nombeko never suspected that her father had TB or that it was very serious. She believed that he would have informed her if it were something to be worried about. There is no way to know where Nombeko contracted TB, but she suspects that she was infected from her father. Since being on treatment and attending support-group sessions, Nombeko has some understanding of the infection, its contagiousness and the necessity of adhering to one's treatment. Given what she knows, she cannot accept that her father abandoned his treatment. In one of our first meetings Nombeko asked me if I would drive her to the Cape Town Port, where her father used to work. She wanted to see if he had left anything there, or ask a co-worker if someone ever saw him taking treatment. We went to his place of employment, where his former employer assured Nombeko that he had not left anything of importance and if he had he would have been in touch with the family. Nombeko remembered that her mother had acquired her father's folder from the clinic, which she kept underneath her mattress at home. When we arrived back at her house she grabbed the folder and asked me to read it to her. A lot of what was written was illegible, but we learned that he was also HIV-positive, which Nombeko had never suspected. The counseling form indicated that he had "accepted" his diagnosis of HIV and would inform his family. Nombeko said,

I'm so angry that I am finding out about these things now that he is gone. I want him to come and visit me so that I can question to him. I ask him to come to me. I think he's scared because I have so much anger with him still. Men are cowards. Why do we need them? The little time I spent with him I was asking if he was ok, I had a lot of questions, that was why I came, but I couldn't ask him because he was sick and he died before I could ask. The only thing that I can say is that he is my father. To say more, I don't know anything about his life. I don't know where I fit in.

Nombeko could not understand why he failed to be honest with her. She reiterated that although treatment is difficult it is better than the alternative, which is premature death. Nombeko never stopped looking for evidence throughout her father's home that would suggest that he was trying to get better or at the very least considered telling her about his conditions.

I never see any TB pills of my father's. There is nothing. The only pills that I can see are headache tablets. There is no trace that he had TB. In my box [she went to grab a shoebox from beneath the bed in the other room] I keep my tablet bags. I don't throw anything away. It's like a way for me to look forward, when I can look back and see myself and what I went through. It makes me have courage and strength. I can never be afraid to look back. Then you can know what is small and what is big. There are bigger things coming to me. So I must be stronger for the bigger ones.

Nombeko's fixation in searching for evidence of her father's experiences with TB – and now HIV – inspired her to retain the empty packets of her own DR-TB and HIV medication as a way of processing her experiences with the infections. Looking at her pile of empty pill packets, she asked me if I could believe that all this “waste” was in her body. She referred to the packaging of the medication as waste, and the pills themselves represented garbage or “toxic” waste in her body. There was something contradictory in these statements, as Nombeko remained dedicated to her treatment despite her occasional modifications. She recognised that there was no alternative to this drug therapy, yet repeatedly said that her body was being “poisoned” or growing “toxic” because of the medication.

UNRAVELING CURE: EXPLORING CONTRADICTIONS

When Nombeko brought her box full of empty pill packets there was a turning point in the way we spoke about pills, emotions and relationships. For Nombeko, the “waste” that had accumulated from these packets just over the past couple of months signified several possibilities: the duplicitous nature of both cure and “toxicant,” a search for answers about her father's death, and her own sense of self-definition. Nombeko asked me what she should do with the pill packets, rather than keeping them stored beneath her bed. The following week I brought markers, tape and glue and several meters of brown paper. I asked Nombeko if she thought she would like to create a collage of her experiences with the illness. I left her with the supplies and made lunch. When I returned she had glued and taped a lot of the packages onto the paper. She turned to me and said, “I need to find a way to heal myself from within. Maybe that's what we're doing here.” I suggested that in the blank spaces she write emotional

reactions or perceptions of the treatment so that she can trace her journey. Over the course of the next few weeks, Nombeko collaged her empty pill packets onto this sheet of paper, adding photographs of people and places that she took when she walked to and from the clinic that made her contemplate abandoning her treatment altogether. Many of the photographs that she included were of her mother and members in the community, and she routinely spoke of how they caused her to miss days of treatment because of abuse and stigma. To safeguard Nombeko's and others' anonymity, I have had to exclude many photographs of this project.



Figure VI: Collage

This collage offers an important description on the emotional relationship that Nombeko had with the material objects of medication. It clearly articulates her sentiments in the presence of a dual process of the toxification of her body while simultaneously acknowledging its positive therapeutic effects. There were days when Nombeko would remark on how she was putting on weight and had more energy compared to when she first started treatment. Nombeko's collage gave an expression to her evolving understandings about the embodiment of DR-TB treatment regimens. Not surprisingly, her reactions to the treatment in its earlier phase were more negative and extreme than subsequent weeks when her body started to grow stronger. "Death sentence" was the first thing that marked the page of Nombeko's collage. I asked her why she wrote that, given that she knew that DR-TB could be cured. She was quick to remind me that if the infection does not kill her, then the pills might. Followed by that

expression she wrote, “this makes me sick,” in reference to the medication, not the infection. She said that even though the packages were empty you could still smell the repugnant scent. Several days later I returned to Nombeko’s home and noticed that she had written, “it gives me hope, but I am scared at the same time” beside a layered arrangement of several pill packets. After having a couple of good days Nombeko explained that she was starting to feel better and was convinced that the pills were “maybe doing their job.” This became a visual tool for Nombeko to trace her treatment journey and remind her that she has experienced better days because of the curative properties in the medication. One of the last things that I noticed on Nombeko’s collage was, “I don’t feel like a woman anymore” and “I wonder if my body will ever be the same.” These two reactions to her treatment resonate with the sentiment that treatment and illness have disrupted her sense of identity and even created uncertainty of what is to come after cure. Observing Nombeko collage these packets over the period of several weeks confirmed how treatment is lived as a state of contradictions.

“MY BODY IS DAMAGED”: THREATENED IDENTITY

I become scared of looking at the mirror because you do not see the person that you know: you see a stranger reflected on that mirror. Its starts with your face, it burns your face and you look totally different from the person that you were.

[Female Focus Group Respondent]

The above remark illustrates the observable manifestations that surface in one’s physical appearance. The transformations in the external body shift one’s perception of self-identity into something unfamiliar and unrecognisable. DR-TB and its treatment can produce a sense of estrangement from both one’s physical-body and sense of self. It therefore becomes a new struggle to redefine and understand one’s social and intimate relations. To explore this perception of alienation, the following section will examine how medication can disrupt female patients’ sense of identity and femininity to produce anxieties about their reproductive health during and post-DR-TB treatment.

Nombeko: Now I can't even see my womanhood because of these injections and these pills. I don't see anything about this treatment as normal. I don't menstruate. I don't get my period! Yeah.

Laura: What does that feel like for you?

Nombeko: It makes me feel empty. You know. Empty as in like... I don't know. Sometimes I feel like I am not human. I'm not even a woman. No wonder people are scared for this. It's got so many outcomes. A lot. I can't talk about menstruating with anyone.

Laura: That's a big thing to be taken from you.

Nombeko: You see it's your womanhood. That's how you see that it's you, and you are a woman. I am scared to talk about my periods because people will assume that I want to get pregnant. [...] For a woman not to see her period is a lot. It does a lot to your mind. They say some of the side-effects can be permanent. What if this is permanent? I am still young. My body is damaged. If I tell others that I am not having my period, they will see me as dirty, because it is not normal for a woman to not have her period. As I was growing up I would show my grandmother when I got my period. Girls do that with their mothers and grandmothers. So imagine if you are not going to period at all.

Laura: Your menstruation cycle is something to be proud of and something that reminds you that your body is working.

Nombeko: Yes of course. Isn't it for you? On that date it makes you very happy. Maybe it's the 13th, but the 13th passes and now it's the 15th and you see nothing in your pants. You are stressing because you can't see your womanhood.

Nombeko's menstruation cycle was a mark of honour and a reminder of her fertility. According to her, DR-TB along with its treatment was to blame for taking this away from her. The sentiment signified a sense of being "empty" or "non-human", a further example of how physiological side-effects from DR-TB and its treatment can disrupt one's identity. The Xhosa customary practice of showing one's mother or grandmother proof of menstruation until marriage is a mark of womanhood. The inability to recognise one's own body in all of its familiar functions that act as reminders of being healthy or being a woman evokes shame.

Nombeko's statement "my body is damaged" is connected to the idea of a "toxic" sense of self, which was discussed during a female focus-group discussion.

Respondent 1: I just want to ask, are they going to check our wombs after we are done with the treatment? Will they?

Respondent 2: There could be a difference across gender lines because women have a more fragile body, which maybe damaged easily. It also affects the menstrual cycle, because I used to take three days in my cycle, now it is six days. The dates to expect your periods also changes.

Respondent 1: I no longer get periods. The treatment also affects my womb because when I get an injection I can feel my womb contracting – like it is shaking – I was saying that we can get damaged bodies more easily as women than men because it will also affect the ability to bear children and issues of pregnancy.

The perception of a "damaged body" that would be inhospitable to a fetus was connected to witnessing the disintegration of the body either through amenorrhea or prolonged and more painful menses. These anxieties surround the personal and social expectations of the female ability to bear children. In some of the female respondents, feelings of tension about the residual damage of treatment upon their reproductive health produced profound anxieties about their future. Symptoms and side-effects have distinct repercussions in female patients as distinct from their male counterparts, which suggests why some women may have a tendency to default on treatment or "tailor" their medication. From comments offered by the focus-group respondents, it was avowed that the female body was more susceptible to damage and more fragile because of its role in reproduction. This sentiment corresponds with metaphors of the female body as more passive or vulnerable, and therefore, female fertility as more predisposed to injury than male fertility (Henderson 2011: 56). The description of a "contracting or shaking womb" offered by Respondent 1 after she received her daily injections is a symbolic and felt reminder of the "natural" functions of the female womb, and a sense of transformation the female body undergoes. Our bodies are the primary sources that shape individual subjectivities and when the body's routine functions are interrupted it can threaten not only the body but also one's sense of personal identity (Pandolfi 2007: 457).

CONCLUDING COMMENTS

MDR is worse than HIV although HIV cannot be cured and TB is curable, but worse. The fact that you have more than twenty different tablets for two years and they are powerful drugs, and then you telling me that I will go back to normal. Seems impractical. You will never go back to normal.

[Respondent 1, in a Focus-Group Discussion]

People encounter events in their lives that radically shift their sense of identity or shake the foundation that frames their reality. By tracing Nombeko's life history I was able to see the ways in which DR-TB and its treatment regimen transgressed into her relationships, reshaped her sense of identity and her confidence in her future. This chapter outlined the many layers of contradictions that emerge throughout an illness episode because of the various possibilities of side-effects. In order to understand why patients have a propensity to default on DR-TB treatment it is necessary to acknowledge the layers of side-effects that disorder the everyday. Through acts of "tailored adherence," patients attempt to manage the physical side-effects to get a sense of control over their body and the uncertainty in their future. Nombeko's narrative captures a struggle with contradictory experiences of treatment where cure runs parallel with the degradation of the body and the self. In Nombeko's illness narrative, it was telling that side-effects span various aspects of her life, how her body responded to the pharmacological compounds of the medication and how treatment interfered with relationships and rearranged her sense of identity. Nombeko's life history demonstrates that describing and acknowledging the existence of side-effects is insufficient to develop an understanding of the interplay between side-effects and emotions and how both emotional and physical side-effects trigger certain patterns and practices of "defaulting" behaviour.

CONCLUSION

The terms default and adherence derive from a public-health ideology that examines individual patients' treatment-seeking behaviour. The clinical classifications function in several ways as they attempt to prescribe or encourage behaviour that will most likely extend a patient's life and protect the broader population from infection. At the same time as these categories attempt to motivate curative behaviour their application in popular and public discourse has become part of an incriminating rhetoric of blame. Consequently, default is pathologised as an individual patient's failure to his or her treatment. The onus of 'good' behaviour is recognised through a patient's commitment to his or her treatment. This dissertation argued that 'default' from a treatment regimen belongs to a history of bureaucratic failings and neglect and not solely to the individual patient. Government bodies, pharmaceutical companies, NGOs and healthcare providers have also been known to 'default' from their commitments to provide sustained, adequate and sensitive care to DR-TB patients. Patient treatment compliance is inseparable from sociopolitical history and past and present. Individual patient behaviour can be read alongside bureaucratic and institutional neglect and lethargy as they all intersect to shape and create an overall experience for every patient. This dissertation provided accounts of patients' experiences of the "in-between" treatment and cure to reveal the contradictions that emerged in individual patient bodies throughout the course of their treatment.

Throughout this research patients described some paradoxical qualities of DR-TB treatment, as they understood it to degrade the very thing it was meant to save – the body. A reevaluation of patients' utterances that "DR-TB treatment doesn't allow you start your life," sentiments of being "already dead," and that treatment and infection are equally understood as a "death sentence" reveals such contradictions. These sentiments are critical for understanding what a commitment to a cure means and how such commitments are enacted when one already has the sense of being dead. To recapture a sense of being alive or in control of their own bodies, patients spoke of their other obligations that suffered because of the physical and

emotional demands of treatment. By observing practices of “tailored adherence” it was evident that many patients developed unique strategies to administer their medication in order to maintain a sense of control over their psychological and physical wellbeing.

I used William James’ theory of “radical empiricism” as an analytic framework as it allowed me to explore the material relations between the various forces that play a role in a patient’s therapeutic regimen. The emphasis on the relational aspects of treatment and cure revealed the profound anxieties about a patient’s future after treatment, given that strict ‘adherence’ to DR-TB therapy may require someone to ‘default’ on other responsibilities (Winterton 2010). The application of the term ‘defaulter’ as a general descriptive category applies to all patients who pause on treatment either for employment opportunities, the emergence of fractious relationship with family and friends, or the abasement of a patient’s very identity. In order to confront the public-health challenges of patient compliance there must be strategies that valorize patients’ articulations of distress and suffering that speak to such complex issues. This dissertation revealed some of the more hidden aspects of individual streams of logic that influence treatment-seeking behaviour. Paying attention to the nuances of such observations could help to establish more specific and applicable counseling programs that address problems of identity, femininity and masculinity, familial obligations, housing and suicide related to DR-TB treatment.

Suffering through contradictions seems to be what happens “in-between” infection and cure. Patients’ expressed memories, imaginations and realities of their pasts, presents and futures that either influenced or determined their treatment-seeking behaviour. More research is needed to explore the specific tropes of contradiction in patient, healthcare workers, and institutional patterns of default and adherence. A more in-depth gender analysis on both physical and psychological side-effects could assist physicians and counselors in finding language to appease such distresses. The politics of healthcare delivery in South Africa are a paramount issue to administering care to vulnerable patients, and a more robust understanding of the rhetoric of blame that thrives in these relationships could help shape new ways of speaking about patient treatment-seeking behaviour.

There is no easy or clear solution to patient treatment adherence, however, there must be sensitive and imaginative dialogue that can address these challenges in ways that will at the very least bring more dignity to those both receiving and delivering care. I would like to leave the final word with an inoculator, who also worked as a political activist in Khayelitsha,

People who don't swallow the pills have no idea how the treatment is overwhelming. You feel depressed, or whatever. So I think that depression spreads to everyone around you and people shout at you when you don't go to take your treatment – they yell at you for stopping treatment. I feel ashamed for someone even when I don't know why he stopped taking the pills. There is a problem behind why he stopped we must find out and stop shouting! Where is the facilitator who leads us past the psychological darkness we have on treatment?

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